Caring for quality

Achterberg, W.P.

2004

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The use of the Minimum Data Set (MDS) for research into quality of care and patient functioning in nursing homes

Wilco Achterberg

VRIJE UNIVERSITEIT

Caring for quality
The use of the Minimum Data Set (MDS) for research into quality of care and patient functioning in nursing homes

ACADEMISCH PROEFSCHRIFT

ter verkrijging van de graad van doctor aan
de Vrije Universiteit Amsterdam,
op gezag van de rector magnificus
prof.dr. T. Sminia,
in het openbaar te verdedigen
ten overstaan van de promotiecommissie
van de faculteit der Geneeskunde
op woensdag 15 december 2004 om 15.45 uur
in het auditorium van de universiteit,
De Boelelaan 1105

door

Willem Pieter Achterberg

geboren te Zeist

promotor:	prof.dr. M.W. Ribbe
copromotoren:	dr. A.M. Pot
	dr. A. Kerkstra

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The study presented in this thesis was performed at the Institute for Research in Extramural Medicine (EMGO Institute) of the VU University Medical Center, Amsterdam, the Netherlands in collaboration with the Netherlands Institute for Health Services Research (NIVEL), Utrecht. The EMGO Institute participates in the Netherlands School of Primary Care Research (CaRe), which was re-acknowledged in 2000 by the Royal Netherlands Academy of Arts and Sciences (KNAW). The study was funded in part by Cascade Zorgcentrum Rosendael, Utrecht and in part by a grant of ZON –MW.

Financial support for the printing of the thesis has been kindly provided by:
Cascade, Zorgcentrum Rosendael;
Alzheimer Nederland;
Nutricia;
and the EMGO Institute.

ISBN 90-6464-680-5

Cover drawing: Max Achterberg

Printed by: Ponsen & Looijen b.v,

Wageningen, The Netherlands

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Appendix : MDS

Outline of this Thesis

Chapter 1 provides background information on nursing home care, nursing home patients, and the MDS-RAI (the Minimum Data Set of the Resident Assessment Instrument, the main instrument used in this thesis. The research questions are set on this stage.
The thesis is divided in three parts.
The MDS-RAI instrument for nursing home care is described in the **first part.** The psychometric properties are discussed **(chapter 2),** and a behavior scale based on MDS-RAI items is constructed **(chapter 3).**
The **second part** contains a review of the effects of the implementation of the MDS-RAI in nursing homes **(chapter 4).** A controlled trial is described on the impact of implementing the MDS-RAI in nursing homes on the quality of co-ordination of nursing care **(chapter 5).**
The **third part** contains four chapters providing insight in patient functioning using MDS-RAI data. There is a need for more research on the growing number of frail elderly nursing home patients to improve the quality of care for these patients. Low social engagement **(chapter 6),** depressive symptoms **(chapter 7)** and pain **(chapter 8 & 9)** are the main objects of study.

In this thesis, both the terms *resident* and *patient* are used. I have been guided in the different chapters by the preferences of the targeted journals. Sometimes the choice is obvious (Alzheimer patient instead of Alzheimer resident). Most of the time however, the use of the term is indiscriminate.
In this thesis, I will refer to nursing home patients and residents with feminine pronouns, as the majority of the nursing home inhabitants are female.

Chapter 1
General introduction

Nursing homes and its population in the Netherlands

The first official Dutch nursing home, "Het Zonnehuis" at Beekbergen, was organized and built as a hospital for chronically ill elderly patients in 1929 (Hertogh et al. 1996). Although there have been a lot of changes since then, a nursing home is still "an institution which provides temporary or permanent multidisciplinary treatment, guidance and support, and nursing care for elderly patients with long-term, complex health problems, expressed primarily in functional disorders and handicaps" (Ribbe 1993).

All nursing homes in the Netherlands are funded under the 1968 Exceptional Medical Expenses Act (AWBZ-Algemene Wet Bijzondere Ziektekosten). The AWBZ stimulated the growth of the number of nursing homes in the Netherlands: in 1964, there were 60 nursing homes, now there are approximately 331 (Ribbe et al.1997, de Pijper et al. 1993, Prismant/VWS 2001). In 2002 there were 66.865 patients receiving nursing home care, at a cost of 4,292 mln Euros (Branche rapporten VWS 2004). In 1990, 'nursing home physician' was recognized as a medical speciality, for which a specialized training program and registration is required (Hoek et al. 2001, Hoek et al. 2003).

Aims and goals of nursing home care

Nursing homes in the Netherlands have several functions. Residence and nursing care, observation and diagnostics, supervision, treatment and reactivation/rehabilitation (Boot & Knapen 1996). Of all newly admitted somatic patients, 36% stay longer than 6 months in a nursing home; 66% of the psychogeriatric patients stay longer than 6 months. Of all newly admitted patients, 33% are eventually discharged home, or to a low-care setting (Ribbe et al. 1995).

The aim of nursing home care is the promotion, preservation or re-establishment of health, functioning and quality of life (Wendte & Danse 1994). Kane et al. (1998) describe three objectives:

1- to achieve clinical improvements (or delay the rate and extension of decline)

2-to provide services to alleviate distress caused by functional impairment

3- to help the individual to fulfill personal life goals.

Therefore, well-being and general functioning usually have the highest priority in the nursing home, whereas in hospital care the focus is on diagnostics and initial treatment of the disease and its complications (Ribbe 1993). There is attention for complex ADL (Activities of Daily Living, like washing, bathing and clothing) and medical problems in nursing home care, but also for the improvement of psychosocial well-being (for instance by introducing activity programs). This focus on well-being has also led to an increased attention to (normalization of) the living environment and to the use of small-scale care units (predominantly for Dementia patients) (Schermer 2003, Ettema 2001). In addition to regular nursing home care, many nursing home patients receive 'nursing home care' in day care, residential homes, or sometimes in their own home (Schols & te Wierik 1993).

Age distribution and future population growth in the Netherlands is comparable to that of other western countries. It is estimated that in 2010 15.4% of the population will be aged over 65 (in the USA this is 13.3%, and in the UK 17.1%) (Ribbe et al. 1997). Of people who are 65 and older, 2.5% live in nursing homes, which is less than in the USA (5.0%), but more than in the UK (2.0%) (Ribbe et al. 1997). In almost all developed countries between 1% and 5% of the population aged over 65 resides in long-term care facilities for handicapped elderly like nursing homes. This suggests that these facilities are indispensable (Ribbe et al. 1997).

Multidisciplinary Care

The limitations and handicaps seen in nursing homes are often on multiple domains: daily functioning (ADL) like bathing, walking and eating, sensory functions (hearing and seeing) and psychological and psychosocial domains. A 'typical' nursing home patient has a chronic condition (for example osteoarthritis, Parkinson's disease, and dementia) with co-morbidity, resulting in ADL impairment, hampered communication skills, disorientation, and confusion or mood problems. Admission to a nursing home leads to the loss of a familiar environment and social contacts, resulting in dependency on others and a loss of autonomy (Patterson 1995).

Dutch nursing homes employ specially trained nursing home physicians, who work in a multidisciplinary team. Such teams also consist of nurses, physiotherapists, speech therapists, occupational therapists and psychologists (Hoek et al. 2000). The name "multi-disciplinary" and "interdisciplinary" are used to describe a situation in which the joined output of several professionals is better than the sum of the separate efforts. This can be accomplished by setting joined goals for the problems of individual patients, and by using the same language when addressing problems, goals and actions (Hertogh et al. 1996).

In nursing home care, these problems are addressed in a care plan. The care plan describes the problems of the patient, the goals to be achieved, and the actions taken to achieve these goals. After a care plan is drawn up, evaluation and adjustment takes place on a regular basis.

Assessment

To meet the needs of (nursing home) patients it is of paramount importance that these needs are assessed. There are many lacunas in the scientific knowledge of patient assessment and its effect on quality of care and quality of life (Wendte & Danse 1994, Sluijs et al. 1993). A review of the literature on multi-dimensional assessment instruments concluded that many authors recognize the need for such instruments. However, this has resulted in very few publications presenting validated and reliable multi-dimensional instruments. The Minimum Data Set of the Resident Assessment Instrument (MDS-RAI) was by far the most extensively tested and evaluated (Holtkamp 2003).

Quality of care in Dutch nursing homes

There is evidence suggesting that there are considerable differences in quality of care between Dutch nursing homes. Undesirable outcomes, such as urinary incontinence and pressure ulcers,

occurred up to ten times more often in some nursing homes (Wagner 1999). Even greater differences have been found in the USA (Rantz et al. 1996). The Care Institutions Quality Act (kwaliteitswet zorginstellingen) of 1996 requires health care organizations to provide effective, efficient and patient-oriented care. Therefore, organizations must develop a quality system to improve and assure the quality of care (VWS 1996). Nursing homes in the Netherlands use several methods for quality improvement, like quality improvement schemes (for example the MIK-V system) and quality certification (Sluijs & Wagner 2000).

The MDS-RAI for nursing home care

After years of serious concerns about the quality of nursing home care, the Congress of the United States instigated a study on how to improve nursing homes' abilities to ensure satisfactory care for their patients (Morris et al. 1990). This study eventually led to a major revision of the federal standards for nursing home care. The bill that accomplished that function in 1987 was entitled the Omnibus Budget Reconciliation Act of 1987 or OBRA '87. One of the key recommendations was the use of a uniform assessment instrument. As there was no instrument satisfying all conditions, a new instrument was developed: the Resident Assessment Instrument (RAI). This is the key instrument of this thesis**.** It has two main and interconnected parts: The Minimum Data Set (MDS) and a set of Resident Assessment Protocols (RAPs). The MDS, the central part of the RAI, is essentially a form with questions about the residents' health, well-being and functioning. The Resident Assessment Protocols are a set of protocols for further analysis of problems, which are frequently encountered in nursing homes. The RAI comes with a manual, (Morris et al. 1991, Morris et al. 1995, Morris et al. 1996) which gives extensive information on how to obtain the clinical information needed for filling out the MDS. It also provides definitions, examples and time frames, which help to make reliable assessments. Chapter 2 of this thesis describes the MDS-RAI in more detail.
Since the mandatory implementation in almost 19,000 nursing homes in the United States in 1992, the MDS-RAI has found its way to many other countries in North America, Europe and Asia (Hawes et al. 1997A, Mor 2004). The RAI was first introduced in the Netherlands in "Het Zonnehuis Amstelveen" in 1992 (Ribbe et al. 1996, Gerritsen et al. 2004).

The added value of the MDS-RAI in Dutch nursing home care

Recognition and prevention of (future) problems in health and well-being

The nursing home patient is at risk of developing serious negative (health and quality of life) outcomes, which can be prevented, like pressure ulcers, depression, delirium and (hip) fractures. These risks are so much higher than in the general aging population, that screening for risk factors for these conditions is not only justified, but in many cases obligatory. The MDS-RAI, as a multidimensional assessment instrument, may be helpful in the assessment of problems and risk factors.

Specific conditions have additional negative outcomes for which they are susceptible, like weight-loss in Parkinson's disease, falls and dehydration in dementia, or thrombosis in hip fracture patients.
The complex synchronicity of health problems usually requires professional advice and assistance for solving problems, and for physical, instrumental and psychosocial adjustments. This calls for good care planning, for which periodical and multi-domain assessment of patients' strengths, weaknesses and problems is essential.
The former reasons for assessment are more or less health related. However, nursing home care is more; it is also about promotion of well-being. Assessment of other aspects, such as religious and spiritual issues, the way time is spent and social interactions is also necessary. Therefore, a multi-domain assessment instrument could be of enormous help for Dutch nursing home care.

Nursing home research

Carrying out research within nursing homes is not an easy task. It is hampered by organizational, professional, ethical and financial issues (Ouslander & Schnelle 1993).
In 1994, the National Committee on Chronic Diseases (Nationale Commissie Chronisch Zieken) ordered a study into the quantity and quality of Dutch nursing home care research. It was concluded that the research between 1985 and 1993 was both fragmented and limited (Wendte & Danse 1994). The same study suggested that the introduction of the MDS in the Netherlands could be one of the remedies. The MDS was believed to produce better data on patients functioning than SIVIS, the registration system that was introduced primarily to produce information for policymaking and management of facilities. For many years, SIVIS was one of the main data sources in nursing home research. Although the SIVIS-participation of nursing homes was high (80% of all nursing homes) and the database was extensive, the data on especially functioning were believed to lack the necessary detail (Wendte & Danse 1994). Others also stressed the need for better and less fragmented nursing home care research programs (Veer de & Kerkstra 1997, Sluijs et al. 1993).

Additional MDS applications

The introduction of the MDS in the USA has lead to the availability of data on functioning of all nursing home residents in the USA. This has expanded the scope of the MDS. In addition to the original goal (aid for care planning), there are now several other applications available:

►case mix and funding based on case-mix (Fries et al. 1994)

►outcome measurement, for example scales for ADL, cognition and depression. These scales are composed of multiple items and can be used to 'rate' a function; this can be helpful in careplanning for setting and evaluating goals (Mor 2004).

►quality indicators (Mor et al. 1998), which are outcome or process measures, that can be compared to other facilities. They are able to suggest that there are problems in the quality of care; examples of quality indicators are the number of pressure ulcers in patients who have a low risk for pressure ulcers; and: the number of depressed residents that receive no (psychological or medical) treatment.

The MDS has also expanded to other domains in health care: an MDS for Home care (MDS-HC) was the first to follow, but there are many others, in different stages of development: Assisted living, Palliative care, Acute care, Post-acute care, Mental Health, Community Mental Health, Persons with disabilities and Intellectual disabilities) (www.interrai.org). This has provided yet another possible benefit and reason for implementation:

►an integrated health information system based on the RAI/MDS series of instruments (Hirdes et al. 1999, Frijters et al. 2001).

These applications go beyond the scope of this thesis, but they have strengthened the MDS as a broad range quality instrument (Frijters et al. 2001), and therefore play an important role in the motivation of nursing homes to implement the MDS (in countries where there is choice whether to implement the MDS).

Part I: The MDS-RAI instrument

The first part of this thesis provides information on the MDS-RAI and the reliability and validity of the instrument for assessing the many problems that nursing home patients encounter (Chapter 2).

Research Question 1 (Chapter 2):

Is the MDS-RAI for nursing home care a reliable and valid instrument for care planning and for research in nursing home care?

Next to reliability and validity, an assessment instrument needs outcome measures, which are practical for care workers to improve the care to the residents (Mor 2004). When the MDS-RAI was introduced in Dutch nursing home care, caregivers on psychogeriatric wards commented on the lack of a behavior scale (Achterberg & Frijters 2003). Therefore, in **chapter 3**, a scale for challenging behavior in the nursing home is constructed and tested. This scale is constructed using the insights of the Social Production Functions (SPF) theory. According to the SPF theory, resident behavior takes place in a social context, and social interaction has to do with the fulfillment of needs (Lindenberg 1996). Every individual is, to some degree, dependent on others to achieve well-being. In nursing home residents, this dependency is much stronger.

If the resident displays 'inappropriate' behavior (like conflict or repetitive behavior), this may evoke irritation, frustration or rejection by others (for instance by staff, family and other residents) (Cohen-Mansfield et al. 1989). This could have a negative influence on their (staff, family other residents) willingness to fulfill resident's well-being goals. In other words: The resources to fulfill resident's well-being are challenged. The aim of this chapter is to create a behavior profile of the resident, which helps the caregiver to ameliorate the circumstances and resources of the resident. This behavior profile should be readily available to many nursing homes, and is therefore constructed with MDS data. The name 'Challenging Behavior Profile' is

preferred to agitated, inappropriate or problem behavior, which all have negative connotations. The name also emphasizes the importance of the reaction of the environment.

Research Question 2 (Chapter 3):
Can MDS-items be used to create a valid scale for behavior based on the Social Production Functions (SPF) theory?

Part II: Improvement of quality of care after implementation of the MDS-RAI

If the MDS-RAI yields reliable and valid data (Part I), it is expected that the quality of nursing home care will improve, but this is not a matter of course: the data may be clinically irrelevant, or the implementation may be too complicated. Therefore, this part studies the effects of implementation of the MDS-RAI in nursing homes. If the quality of care improves, it is expected that this will have a positive impact on health and quality of life (Donabedian 1985, Holtkamp et al. 2000). This part studies the implementation of the MDS-RAI with regard to the process of care, and patients' health and quality of life. **Chapter 4** describes a literature study of these effects. **Chapter 5** describes a non-randomized controlled intervention study, which was performed on eight wards in Dutch nursing homes, which implemented the MDS-RAI, and eight control wards. This included 348 somatic patients. The study deals with the effects of implementation of the MDS-RAI on the quality of care, especially the co-ordination of nursing care. An instrument for measuring quality of nursing care in Dutch nursing homes has been developed and validated which focuses on three aspects: Co-ordination of care, instrumental/technical aspects and environmental/living aspects (van Lingen et al. 1990). Co-ordination of care is here divided into six main quality aspects: Taking case history on admission, content of the care plan, end of shift report, communication (between nurses and other caregivers and patient), patient allocation and the content of the patient report. These aspects are strongly related to procedures at ward or facility level, and therefore these scores are an indication of the quality of co-ordination of care at the ward/facility level. Considering the quality aspects and procedures of the MDS-RAI method, it was expected that improvements should be found in the quality of taking a case history, the care plan, patient report and communication (van Lingen et al. 1990).

Research Question 3 (Chapter 4):
What are the effects of the implementation of the MDS on the quality of care and patient functioning in nursing homes?

Research Question 4 (Chapter 5):
Does the implementation of the RAI method improve the quality of the co-ordination of nursing care in Dutch nursing homes?

Part III: Insight in patient functioning using MDS-data

The third part of this thesis focuses on epidemiological studies using data obtained from nursing home patients with the MDS-RAI.

Epidemiological studies are helpful in exploring relationships between (negative or positive) outcomes and their determinants (Bouter & van Dongen 1995). These relationships are often complex, and not fully understood for nursing home patients because of their extensive co-morbidity (Fried & Guralnik 1987, Miller et al. 2000). It is important to enlarge our knowledge of these relationships, because this may help the nursing home professional to "do better"-: Better assessment, better treatment, advice, care practices, with the ultimate goal to improve the quality of life of nursing home patients.
This part concentrates on three problem areas: Depressive symptoms, pain and low social engagement. They are serious, highly prevalent and 'difficult to manage' conditions and they provide a major challenge for long-term care settings like nursing homes. All three conditions are multi-factorial in origin and may influence health and quality of life.

Chapter 6, 7, 8 and 9 are based on data that were gathered by nursing home physicians in training. They gathered data of 562 newly admitted residents in 65 nursing homes through the Netherlands.
The effect of depressive symptoms on social engagement in newly admitted Dutch nursing home residents is studied in Chapter 6.
Being successful in social engagement is a critical component of quality of life for nursing home residents (Mor et al. 1995). It means that a resident has a high sense of initiative and involvement, can respond adequately to stimuli in the social environment and is able to participate in social activities and to interact with other residents and staff. Previous research has associated low social engagement with increased mortality (Kiely et al. 2000, Bennett 2002) and cognitive decline (Bassuk et al. 1999). The hypothesis under investigation is that depressive symptoms may hamper the residents' ability to be socially engaged. Depressed residents are likely to have more difficulty in engaging themselves in the new environment. Depressive symptoms (such as anxiety, withdrawal and loss of interest) can act as obstacles to the receptiveness of a resident in responding to social stimuli. Previous research has been based on samples that had been in the nursing home for a variable period of time (Mor et al. 1995, Schroll et al. 1997, Resnick et al. 1997; Frijters et al. 2001). Little is known about the predictors, course and prevention of low social engagement. It is important to study the concept of low social

engagement in newly admitted residents, because knowledge in this field may facilitate the development of preventive strategies.

Research Question 5 (Chapter 6):
What are the effects of depressive symptoms on social engagement in newly admitted Dutch nursing home residents?

Depressive symptoms and depressive disorders are highly prevalent in nursing homes, much more so than in community-dwelling elderly (Jongenelis et al. 2003), and the impact on quality of life, mortality and costs of health care is considerable (Beekman et al. 2002). There has been scarce research on the impact of nursing home admission on the development of depressive symptoms (Lee et al. 2002). Placement in a nursing home requires an extensive adjustment process, and therefore may be a stressor, which can induce depressive symptoms (Patterson 1995).
Chapter 7 is a study of the level of depressive symptoms in residents, which were admitted from home, compared to residents that were admitted from other care settings (like a residential care setting or hospital). It is based on the hypothesis that being admitted from home is a more stressful life event, and therefore may lead to more depressive symptoms. This is because of a greater loss in several respects: a loss of autonomy and confidence but also a loss of possessions and one's own familiar environment. The previous place of residence was analyzed as a predictor for depressive symptoms in newly admitted nursing home residents

Research Question 6 (Chapter 7):
Is the previous place of residence a predictor of depressive symptoms in newly admitted nursing home residents?

The last two chapters are studies on pain.
Pain is highly prevalent in nursing homes (45-80%), has a serious impact on quality of life and functional impairment, while the management of pain is not particularly good (Ferrell 1995, Frampton 2003). There is an increase in pain related pathology with advancing age, and although this could mean older people experience more pain, they appear to report less pain (Frampton 2003). Experience and report of pain depend on many things, like mood state, perception of control, expectations, and social or cultural conditions (Turk & Okfuji 1995).
It is important that clinicians appreciate the complex relations between dementia and pain, because pain is a treatable nuisance and a possible cause of behavioral problems (Geda & Rummans 1999). The relation between pain and dementia is interesting, because of several phenomena: Alzheimer patients appear to have less pain, whereas patients with vascular dementia are thought to be in risk for pain, induced by white matter lesions in the brain (Scherder et al. 2003). Most nursing home residents with dementia have had no Magnetic Resonance Imaging (MRI) of the brain, which is the only way to show these white matter

lesions. Pain assessment and management in nursing homes could be improved if we could use a simpler measure than MRI to estimate these white matter lesions. Understanding the differences in the experience of pain in different dementias might improve assessment and management. **Chapter 8** therefore studies cardiovascular risk factors as a measure for white matter lesions and investigates the relationship with cognition and pain.

Research Question 7 (Chapter 8):

Is pain prevalence different in the following three groups: cognitive intact patients, cognitive impaired patients with CRF (cardiovascular risk factors) and cognitive impaired patients without CRF?

We need more insight into factors that influence the assessment and management in dementia patients (Ferrel et al. 1995, Frampton 2003). One of these factors might be the environment. Assessment and management of pain in pediatrics can be improved when the attention is simultaneously on individual caregivers and environmental factors like ward and institution (Jordan-March et al. 2004). In that study, multiple interventions were introduced simultaneously at different levels: The introduction of a pain assessment tool, a change in drug prescription policy, education, and multidisiciplinary rounds. In the Netherlands, residents with dementia are admitted on specialized psychogeriatric wards and residents with other diseases are often separated in long-term care, palliative or rehabilitation wards. The specialized psychogeriatric wards are comparable to the Special Care Units (SCU) for Alzheimer disease in the USA. SCUs pay special attention to behavioral interventions while minimizing psychotropic medication and the use of restraints. It is unknown what the quality of pain assessment and pain management is compared to other nursing home facilities with a more physically oriented care. (Gerdner & Beck 2001, Kane et al. 1998, Warren et al. 2001, Lane et al. 2003) Therefore, **Chapter 9** is a study on pain in three different types of care units: rehabilitation, somatic and psychogeriatric wards.

Research Question 8 (Chapter 9):

Does the type of special care ward influence pain assessment and management?

Finally, in **Chapter 10 (General discussion and summary),** the results of all of the studies mentioned above are integrated and discussed.

PART I:

THE MDS-RAI

Chapter 2
The MDS-RAI: Introduction, reliability and validity*

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* This is a revised and updated version of the article:

Achterberg W, Pot AM, van Campen C, Ribbe M. *Het Resident Assessment Instrument (RAI): een overzicht van internationaal onderzoek naar de psychometrische kwaliteiten en effecten van implementatie in verpleeghuizen.* Tijdschr Gerontol Geriatr. 1999; 30(6):264-70.

Summary

This article is a review of the available literature on psychometric qualities of the Minimum Data Set (MDS) of the Resident Assessment Instrument (RAI). The MDS-RAI is developed in the USA to assess the needs of nursing home residents. It consists of a comprehensive assessment of the resident (the Minimum Data Set) and 18 protocols (Resident Assessment Protocols) for further analysis of major problem areas. The MDS-RAI is implemented in nursing homes in the United States, Canada, Japan and several European countries. The interrater reliability ranged between adequate and excellent for clinical use in several studies. The validity is good for the assessment of ADL- and cognitive functions, but moderate for mood and behavior.

Introduction

The Resident Assessment Instrument (RAI) for nursing home care is an instrument that has been developed for standardized comprehensive assessment of nursing home residents (Morris et al. 1990). The information gathered with the Minimum Data Set (MDS) of the RAI can be used to create an individualized care plan (Morris et al. 1991, Morris et al. 1995, Morris et al. 1996).

When these patient data are aggregated, they can also be used for research, for the assessment of the quality of care by way of quality indicators and determine case-mix indices of individual patients, wards or institutions (Hawes et al. 1997A).

The MDS is mandatory implemented in 19000 nursing homes in the United States in 1991, after serious concerns about the quality of nursing home care. American Congress decided that this was an essential part of a program to improve the quality of care and quality of life in nursing homes. The MDS-RAI has been translated in 15 languages, and is used for the assessment of frail elderly in the United States, Canada, Japan and 12 European countries (Hawes et al. 1997A).

Fourteen nursing homes use the RAI in the Netherlands (June 1st 1999), including the academic nursing homes affiliated with the Vrij Universiteit Medical Centre Amsterdam. In addition to the possibilities for quality improvement in everyday care, other applications of the MDS-RAI for benchmarking with quality indicators have been an important reason for these institutions to implement the MDS-RAI (Ribbe et al. 1996).

The MDS-RAI is described in this article because of this implementation and the growing interest of nursing homes and researchers. The following question is answered based on the available literature: What is the reliability and validity of the MDS?

Methods

All available (English- and Dutch) literature in the period 1990 - January 1999 in Medline, Embase, Current Contents en Psychlit (keywords: Minimum Data Set and Resident Assessment Instrument) on the psychometric qualities of the MDS-RAI have been used to answer the questions. Weighed Kappa's are used (> 0.4- reasonable, > 0.6 = good) for the discussion of the interrater reliability, and Pearson correlations of RAI items/subscales with other instruments for the validity (Altman 1997).

Results

The Resident Assessment Instrument (RAI)

The RAI consists of the Minimum Data Set (MDS) and 18 Resident Assessment Protocols (RAP's). The Minimum Data Set (MDS) is a structured and comprehensive questionnaire which produces a large amount of information about a resident. The questions comprise information on several aspects of the patients' functioning, health, well-being and behavior. This information is collected by observations of care-givers and interviews with residents and family members. Items are bundled in sections, for instance 'cognitive performance' and 'mood' and 'behavior' (see table 1).

A full MDS is filled out within two weeks after admission, after one year and/or when there is an important change in health status. A comprised version is administered quarterly. The MDS is filled out primarily by nurses, but also physicians and other caregivers (like therapists) can take an important role in this process. Administering the MDS takes about 30-45 minutes for an experienced nurse. The RAI-manual contains definitions of the ordinal scores of MDS items, suggestions for interview techniques and other forms of support for the assessment process (Morris et al. 1995, Morris et al. 1996).
MDS-items deal with the absence or presence of a condition (for instance pressure ulcers), change in condition (no change in mood/worsening/improvement), frequency (no pain/less than daily pain/daily pain), intensity (no pain, moderate pain, from time to time excruciating pain) or degree of care dependency (no assistance, only setting out, physical assistance by 1 person, physical assistance by 2 persons). Combination of the outcomes of the MDS items may refer to problem areas which are important in nursing home care: the Resident Assessment Protocols (RAPs). For example, the RAP 'falls' is triggered when the MDS-item 'dizziness' is present. This provides a list with essential problems which can be used in the multidisciplinary team meetings to make a care plan. The RAPs give directions to further analysis of the problem areas (further physical or laboratory examination, possible causes and context) and they contain suggestions for optimal care. This structured inventarisation of problems is the basis for the creation of an individual care plan (Morris et al. 1990, Ribbe et al. 1996).
In table 1 the MDS domains and RAPs are listed. Figure 1 shows a schematic representation of the way the RAI-method works: Assessment with the MDS→ after filling this out, certain items trigger (or signal) certain problem areas → protocols for assistance in analysis and care planning. Box 1 gives an example of the assessment of a patient with the MDS-RAI.

Several Dutch nursing homes that use the MDS-RAI also in addition use the SFMPC-model *(sociaal, functioneel, maatschappelijk, communicatief)* to arrange the problems, and illuminate relations between problems (Ribbe et al. 1996, Hertogh 1997).
A single MDS item can refer to a problem area (RAP), but there are also scales for the classification of the condition of the resident, which are constructed from several MDS-items, for instance for cognition (Cognitive Performance Scale) and mood (Depression Rating Scale). This makes it easier to monitor changes in the residents' condition in time. There is software available for the filling out of the MDS and the triggering of the RAPs.

Validity MDS
Validity of parts of the MDS has been investigated in 14 studies (Crooks et al. 1995, Frederiksen et al. 1996, Thapa et al. 1996, Swanson 1995, Arvidson-Bufano et al. 1996, Phillips & Morris 1997, Gambassi et al. 1998, Hartmaier et al. 1995, Blaum et al. 1997, Lawton et al. 1998, Brandeis et al 1997, Hartmaier et al. 1994, Morris et al. 1994, Mor et al 1995). MDS-items are grouped on specific domains, like cognition, ADL, mood and behavior, often there are scales constructed with these items in these studies. Several of these grouped items have been compared with other

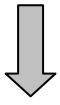
valid instruments. *Cognition* is compared in 4 studies with in total 6 other instruments, *ADL* in 3 studies (compared to 1 instrument), *mood* in 2 studies (6 instruments), *behavior* in 2 studies (3 instruments), *communication* and *time spending* both in 1 study (1 instrument).

Table 1: Sections of the Minimum Data Set (MDS) and the 18 resident assessment protocols (RAPs)

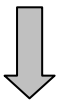
Minimum Data Set section (MDS)	**Resident Assessment Protocols (RAPs)**
Background and customary routines	Delirium
Communication/hearing patterns	Visual function
Physical functioning and structural problems	ADL functional/rehabilitative potential
Mood and behavior patterns	Psychosocial well-being
Disease diagnoses	Behavior problem
Oral/nutritional status	Falls
Skin condition	Feeding tubes
Special treatments and procedures	Dental care
Cognitive patterns	Psychotropic drugs
Vision patterns	Cognitive loss/dementia
Continence	Communication
Activity pursuit patterns	Urinary incontinence and indwelling catheter
Health conditions	Mood state
Oral/dental status	Activities
Medication use	Nutritional status
	Dehydration/fluid maintenance
	Pressure ulcers
	Physical restraints

Figure 1: Outline of the RAI method

Quarterly Assessment with the **MDS** of many domains of functioning



MDS items **TRIGGER** certain important problem areas, indication that there is possible need for further analysis



RESIDENT ASSESSMENT PROTOCOLS assist in further analysis of the problem area

Box 1: Example of how the RAI can be used in multidisciplinary team meetings: Mrs. F.

BOX 1 Mrs. F

Mrs. F, 75 years old, since 8 years in nursing home R. because of ADL dependency after a stroke. After filling out the MDS, the following RAPs (problem areas) are triggered:

1- *Urinary-incontinence/Catheter*
- Triggered because of the MDS item:
- **bladder-incontinence**

2 –*pressure ulcers*
- Triggered because of the MDS item:
- **Bowel incontinence**

***3*- Activity pursuit**
- Triggered because of the MDS item:
- **-Awake most of the time the morning**
- **-No time involved in activities**

***4*- Psychosocial wellbeing**
- Triggered because of the MDS item:
- **-Establishes own goals**
- **-strong identification with past roles and life status**
- **daily routine very different from own home**

5- *Cognitive impairment/dementia*
- Triggered because of the MDS item:
- **-Problem with short-term memory**
- **-Problem with long-term memory**
- **-Problem with decision making (modified independence)**

In the multidisciplinary team meeting, Mrs. Fs' condition is being discussed on the basis of these triggers, and the resident assessment protocols that are create for these problem areas. :

Ad 1: Incontinence is present for many years, and extensively analyzed in the past. The recommendations for the analysis of the cause of the incontinence as mentioned in the RAP, are not necessary now.
Mrs. F is satisfied with the materials used to collect the urine, and so this is no active problem.

Ad 2: Mrs. F has a higher risk for developing pressure ulcers because of the bowel-incontinence, this was not recognized previously. A special mattress and sitting adjustments are ordered.

Ad 3- Mrs. F is capable of entertaining herself, among others with a musical instrument. Group activities are not her 'cup of tea'. After going through the Activities RAP, some caregivers remark that Mrs. F gradually takes on less challenges. New possibilities for individual activities (for instance e-mail and internet) will be discussed with her.

Ad 4: The first item (pursues own goals) is a positive item: caregivers should use this positive aspect of Mrs. F. The physiotherapist mentions that Mrs. F has asked her to make a restart with the therapy. Mrs. F will be asked to formulate her own goals for this therapy.

Ad 5: These mild cognitive problems are present since the stroke, they have been analyzed 7 years ago (neuropsychological testing) and appear to be stable over time. It is important to measure the change over time, therefore testing is repeated.

Psychometric qualities of the MDS-RAI

There were 6 publications with regard to interrater reliability until January 1999 (5 on MDS 1.0 and 1 on MDS 2.0)(Morris et al. 1990, Hawes et al. 1995, Phillips et al 1993, Sgadari et al. 1997, Morris et al. 1997, Casten et al. 1998). A summary of a number of studies in several countries on the MDS 1.0 (the first operational version of the MDS) reliability has been published (Sgadari et al. 1997). Considerable international differences are described in that article: for example, the (weighed) kappa's for the MDS Mood section range between 0.44 and 0.93, for behavior between 0.34-0.81, for nutrition 0.43-0.99, for ADL 0.61-0.92 and continence 0.58-0.95.The patients that are selected for the reliability studies are not randomly selected, because the condition that is measured should have reasonable prevalence and variance. Therefore, pressure ulcers, feeding tubes and delirium are relatively over-represented (Hawes et al. 1995). For a lot of items, especially those which ask for communicative or sensory skills, reliability is lower in cognitive impaired residents (Phillips et al. 1993). A number of items from the MDS 1.0 which had a lower reliability are changed and items which were missed in every day care are added in the latest version of the MDS, the MDS 2.0, which is also the one that is in use in the Netherlands. This MDS has a better reliability: Of 42 new items, 2.4% scored <0.4 (weighed kappa), 16.7% between 0.4-0.6, 47.6% between 0.6-0.8 and 33.3% > 0.8. Of 8 revised items, 12.5% was smaller than 0.4, 12.5% between 0.4-0.6, and 75% between 0.6-0.8. Only instructions, examples or definitions were changed for 82 items: Mean kappa's improved by 18% (from 0.67 in the MDS 1.0 to 0.79 in the MNDS 2.0) (Morris et al. 1997). Most reliability studies are done in a special research setting, where raters have had a special training by the research group. The reliability was however also satisfactory in a regular practice setting: lowest kappa for depression (0.56), highest for inadequate behavior (0.84) (table 2) (Casten et al. 1998).

Mood (r=-0.10-0.44) and behavior (r=0.24-0.54) generally show the lowest Pearsons' alpha, whereas ADL (r=0.58-0.89) and cognition (0.43-0.86) have the highest (Frederiksen et al. 1996, Thapa et al. 1996, Hartmaier et al. 1995, Blaum et al. 1997). Table 3 summarizes these results.

There have been comparisons with other ways of assessing and other assessors. The MDS assessment was very different from the assessment of vision from an ophthalmologist (kappa 0.18) (Swanson 1995). The concurrence between the MDS denture items and the opinion of a dentist was 59%, after a short training this was 81% (Arvidson-Bufano et al. 1996). The incontinence items had a reasonable concurrence with actual incontinence if it was scored by research-assessors, (correlation coefficient r = 0.49), but less than modest when it was assessed by everyday nursing home staff (r = 0.003) (Crooks et al. 1995).

Table 2: Interrater reliability (weighted kappa's) of some key Minimum Data Set (version 1.0 en 2.0) sections and reliability in a regular care setting

	MDS 1.0 (n=24-129) (Sgadari et al. 1997)	**Care setting (n=187) (Casten et al. 1998)**	**MDS 2.0 (n=84) (Morris et al. 1997)**
Cognition	0.47-0.88	0.63	0.68
ADL	0.61-0.92	0.61	0.71
Mood/depression	0.44-0.93	0.56	0.68
(problem) behavior	0.34-0.81	0.84	0.72

Discussion

The RAI is an instrument to analyze the patients functioning, her potential problems and needs, and it provides guidelines for further analysis and course of action for caregivers. The studies that have been performed on interrater reliability show remarkable different results in reliability and profound international differences. The kappa for mood in Japan is 0.45, and in Switzerland 0.93 (Sgadari et al. 1997). In addition to cultural and environmental differences, also the research design probably played a part in these differences. The second assessment was on the same day in Switzerland, the second assessment was after 14 days in Japan. Also the numbers of participants in the studies are very different (between 14 and 129). Most MDS items achieve good reliability, especially the latest version (MDS 2.0), and also in regular care settings. In the psychosocial areas, like mood and behavior relative weaknesses are present.

This review concludes that the validity is not for all domains of the MDS identical. Good validity has been found for ADL and cognition, but mood and behavior score less satisfactory. Some problems with the validity studies in the United States are related to flaws in the assessment process: sometimes staff that fill out the MDS is not the staff that takes care of the resident (the assessment process becomes an administrative answer to the mandatory MDS). This explains the finding that the assessment of incontinence is much better when performed by researchers, then by regular nursing home staff (Crooks et al. 1995).

Supplement: update reliability/validity

Many papers on (psychometric qualities of) the Minimum Data set have been published since this study was published (1999). To illustrate the MDS publication and research 'boost': a Medline search in 2004 (June 25th) with the combination of terms "Minimum Data Set" and "Nursing Home" limited to publications before January 1st 1999 yielded 108 publications. In 5 years, this was more than doubled: 293 articles. An additional 30 articles that did not appear in Medline were used in the most recent review (Mor 2004).

In the largest field reliability testing until this far, 85% of the MDS items had kappa > 0.6. (Mor et al. 2003) The items that scored below 0.6 were very low prevalence binary indicators, showing high levels of agreement. However, it is noteworthy that there was substantial interfacility variation in the reliability for certain items. For example, pain was inadequate reliable in one quarter of all facilities, ADL reliable in all facilities (Mor 2004).

The psychometric properties of several MDS based observational scales in the Netherlands were reported recently (Gerritsen et al. 2004).

The MDS ADL hierarchical scale had excellent reliability: intrarater and interrater reliability of the items kappa > 0.80, intra- and interrater intraclass correlation coefficients > 0.80, internal consistency was 0.84. The MDS Cognitive Performance Scale (CPS) also performed excellently: intrarater and interrater reliability of the items kappa > 0.78, intra- and interrater intraclass correlation coefficients > 0.80, internal consistency was 0.74. The reliability of the MDS Depression Rating Scale (DRS) was lower: intrarater and interrater reliability of the items kappa > 0.50, intra- and interrater intraclass correlation coefficients > 0.71, internal consistency was 0.73. These are encouraging results, considering that the reliability of observational scales for psychosocial concepts is usually somewhat lower, as behavior is more difficult to observe than ADL.

The validity of the MDS ADL scale was very good: the correlation with the Modified Barthel index was 0.77 (spearman's rho). The MDS CPS had comparable good validity: compared to the MMSE 0.76, against the Cognitive Screening Test 0.77. The validity of the DRS against the Geriatric Depression Scale (GDS) for cognitive reasonable intact residents (MMSE > 15) is reasonable (0.54). For cognitive impaired residents, the study was not conclusive.

Depression

The MDS-DRS performed better (more sensitive and more specific) than the GDS in one sample (Burrows et al. 2000). The MDS-DRS was found to have acceptable specificity but low sensitivity, compared with the GDS and Hamilton depression rating scale in another study, (Anderson et al. 2003). The internal consistency of the MDS-DRS was low (Cronbach Alfa: 0.67) in that study, - for example much lower than in our study (0.87-see chapter 7). This raises questions about the reliability of these data. Two other studies concluded that their incongruent findings on the MDS depression indicators may be reflective of the assessment process: the practice of nondirect caregivers completing the MDS, or 'assessment nurses' hired to take the responsibility for 'paper complicance' (Schnelle 2001, Engle et al. 2001)

Pain

The accuracy of the measurement of pain with MDS items has been established in a large nursing home sample against a Visual Analogue Scale (kappa .707) (Fries et al 2001). Fisher and Cohen-Mansfield have found problems in the validity of the MDS pain-items for cognitively impaired residents (Fisher et al. 2002, Cohen-Mansfield 2004), while Cadogan found that the MDS pain quality indicator (using MDS items) accurately discriminates prevalence of pain between facilities (Cadogan et al. 2004). Engle documented fair to good reliability estimates for pain, although Licenced Practical Nurses (LPN), and Nursing Assistants (NA) underestimated both the intensity and the frequency of pain (Engle et al. 2001). This study also found that the NA assessments were more reliable than the LPN assessments. Residents' characteristics (like age, sex, race and depression) did not influence the reliability.

Conclusion update:

Reliability studies on the MDS show divergent results. There are several explanatory factors. The considerable heterogeneity of the results over the different facilities is noteworthy for almost all studies using multiple facilities (Mor 2004). The training of the assessor, the setting (research or regular care) and proximity to the resident (involved in actual care giving) may be the prime explanations for these differences (Schnelle et al. 2001, Engle et al. 2001). The level of cognitive performance also influences the reliability of most items (Stineman & Maislin 2000, Gerritsen et al. 2004, Snowden et al. 1999, Phillips et al.1993).

It would be interesting to study the hypothesis, that results on reliability and validity by and large reflect the facilities' intend to use the MDS for clinical or research practice, instead of only complying to mandated administration. The extended use of MDS data for management (quality indicators, bench marking, funding based on resource utilization groups) may actually improve overall reliability of the MDS.

Table 3: Correlations between some Minimum Data Set sections and other instruments

	Cognition	ADL	Mood	Behavior	Communication	Spending time
Blessed Information Concentration measure of mental status (Hartmaier et al. 1995)	0.66					
Lawton and Brody Physical Self-Maintenance Scale (Casten et al. 1998, Crooks et al. 1995, Hartmaier et al. 1995)		0.58-0.89				
Raskin Depression Ratings (Hartmaier et al. 1995)			0.26-0.44			
Mattis Dementia Rating Scale (Hartmaier et al. 1995)	0.43					
Reisberg Global Deterioration Scale (Phillips et al. 1997, Hartmaier et al. 1995)	0.59-0.80					
Multidimensional Observation Scale for Elderly Subjects						
-irritability						
-depression (Hartmaier et al. 1995)				0.36		
			0.44			
Geriatric Depression Scale (Hartmaier et al. 1995)			0.15			
Cohen-Mansfield Agitation Inventory (Hartmaier et al. 1995)				0.24-0.37		
Philadelphia Geriatric Centre/ negative Affect (Hartmaier et al. 1995)			-0.10			

Philadelphia Geriatric Centre/ Positive Affect (Hartmaier et al. 1995)					0.24
Mini-Mental State Examination (Casten et al. 1998, Crooks et al. 1995, Phillips et al. 1997)	0.53-0.86				
Brief Psychiatric Rating Scale		0.20			
f1= withdrawn depression	0.85				
f3=cognitive dysfunction			0.51		
total= psycho-pathological behavior(Hartmaier et al. 1995)					
Psychogeriatric Dependency Rating Scale (behavioral portion) (Casten et al. 1998)			0.54		
Psychogeriatric Dependency Rating Scale (communication) (Casten et al. 1998)				0.62	
Dementia Mood Assessment Scale					
-(1-17= mood)		0.20			
-(18-24= level dementia) (Casten et al. 1998)	0.50				

(Continuation of table 3)

Chapter 3
The MDS-RAI Challenging Behavior Profile *

*Submitted for publication as: Debby L. Gerritsen, Wilco P. Achterberg, Nardi Steverink,
Marcel E. Ooms, Dinnus H.M Frijters, Miel W. Ribbe.
The MDS-Challenging Behavior Profile: an innovative approach for long term care

Abstract:
The objective was to construct a reliable and valid behavioral scale with psychosocial items of the MDS. Based on the Social Productions Functions (SPF) theory, challenging behavior can be linked to (social) well being of the resident. This link may improve the understanding and the management of such behavior by the nursing staff and other care givers. Five clinical experts selected MDS items concerning resident behavior that may evoke reactions such as irritation, frustration and/or rejection from staff, other residents and/or visitors. This would, according to the SPF theory, undermine their willingness to fulfill the residents' needs with regards to wellbeing.
Exploratory factor analyses of a sample of 656 nursing home residents yielded a 15-item scale, the Challenging Behavior Profile (CBP), that contains four internally consistent and valid subscales, measuring Conflict behavior, Withdrawn behavior, Restless and Repetitive behavior, and Claiming behavior, On a second dataset of 227 nursing home residents, reliability (internal consistency and interrater reliability) and validity against the Behavior Rating Scale for Psychogeriatric Inpatients (GIP) was established. Internal consistency of the overall scale was 0.78 (alpha), the new subscales ranged between 0.53 and 0.78. Overall inter-rater reliability of the items was 0.53 (kappa), of the scale 0.75 (ICC).
The Challenging Behavior Profile has the potential to be an important contribution to the existing clinical MDS-scales.

Introduction

In long term care research, various instruments have been developed in the last fifteen years for measuring so-called 'inappropriate' behavior of residents (mostly with dementia). This behavior goes under various names, like agitated behavior (Cohen-Mansfield & Billig 1986, Sinha et al. 1992, Finkel et al. 1993, Bliwise & Lee 1993, Rosen et al. 1994), problem behavior (Ray et al. 1992), obstreperous behavior (Drachman et al. 1992), behavior disturbances (Gauthier et al. 1996); dysfuntional behavior (Molloy et al. 1996), behavioral pathology (Reisberg et al. 1996), disruptive behavior (Beck et al., 1998), and challenging behavior (Allen-burge et al. 1999). The behavior in question is often negatively labeled, but it is not certain why and for whom it is negative. Moreover, most approaches used in research do not accurately differentiate between the behavior itself, its implications for the resident, and the possible causes of the behavior. Therefore, it is difficult to both understand and intervene in this behavior.

Several approaches and measures, among which is the 'Behavioral and Psychological Symptoms in Dementia' approach (Finkel 2000, Lawlor 2002), partly move away from the behavior itself ('behavioral') and mix it with indicators of its causes ('psychological'). This is puzzling, because typically, every psychological symptom will have its behavioral expression. For example, delusions are an obvious psychological symptom when a resident repeatedly expresses that people are following her. Apparently, when the behavior is clearly related to a psychological cause or syndrome (in this case, delusions), some approaches move away from the behavior itself and formulate items at the psychological symptom level (e.g. DBRI: Molloy et al, 1996; BEAM-D: Sinha et al. 1992; COBRA: Drachman et al, 1992: BEHAVE-AD: Reisberg et al. 1996).

In addition, various approaches aim to exclude 'cognitive disturbances' from behavioral scales (e.g. Reisberg et al. 1996, Auer et al. 1996; Tariot et al. 1995, Lawlor 2002). Cognitive disorders may cause typical behavior, for instance putting things into places where they don't belong. When the behavior is directly attributable to cognitive deterioration, it is often not included in a measure of challenging behavior, irrespective of its 'inappropriateness'.

In long-term care, 'behavior' can be the expression of various syndromes and symptoms. Most long-term care residents are very impaired and have a lot of co-morbidity, making the precise cause of the behavior often far from clear. It is, therefore, difficult to employ 'the' cause of behavior in measurement and intervention strategies. Understanding, measuring and intervening in challenging behavior may benefit more from an approach in which the factual behavior and its possible implications for the resident are considered, because these give practical clues for intervention.

Insight in the implications of challenging behavior can be obtained by starting from the perspective that resident behavior takes place in a social context, and that social interaction has to do with the fulfillment of needs. This perspective is taken by, among others, the Social Production Functions (SPF) theory (Lindenberg 1996, Steverink et al. 1998, Gerritsen et al. in press). Following the SPF theory, challenging behavior can be linked to, and is foremost about, the well-being of the resident. It threatens the achievement of well-being needs, although the

behavior may in itself not be problematic for the resident. One of the theory's basic views clarifies the magnitude of challenging behavior. It describes that every individual is aimed at fulfillment of well-being needs, and for that uses resources (i.e. 'things' that she has and does to achieve well-being, for instance food, health care, money, a spouse, but also cognitive and ADL functioning, or social activities). Every individual is, to some degree, dependent on others to realize well-being, but in long term care, this dependence may be much stronger. Whereas for social well-being, every individual's social needs need to be fulfilled by others, the resources of a long term care resident decrease so strongly that a resident has very limited possibilities to fulfill her needs, even very basic needs, and needs others to help her with that. Given this extreme dependence on others for (social) well-being, if the resident's behavior evokes irritation, frustration and/or rejection, the willingness of people surrounding the resident to fulfill her well-being needs or resources is challenged. This challenging behavior is thus a huge threat to the resident's well-being.

In this paper, the aim is to develop a screening instrument for challenging behavior and investigate its validity using the views of the SPF-theory. This implies that it measures behavior, irrespective of its possible causes, that may cause others to be reluctant to meet the resident's well-being needs. Next to an internally consistent overall scale, the possibility of developing sub-scales is studied, which would provide a behavioral profile with information about what type of challenging behavior the resident expresses. This would give clues for subsequent intervention. The MDS of the Resident Assessment Instrument (RAI) is an obvious item source, as it is used in daily nursing care in many long term care facilities and its behavioral items have good reliability and validity (Morris et al. 1990, Hawes et al. 1995, Frederikson et al. 1996, Snowdon et al. 1999, Snowdon et al. 2003).

The paper is divided in two parts. In the section Scale design a scale is constructed based on a sample of nursing home residents. In the section Validity, the validity of the resulting scale is determined on a second sample.

Scale design

Methods

Five clinical experts independently selected MDS-items to fit the challenging behavior approach as suggested in the introduction. This means that they selected items on resident behavior that may evoke reaction such as irritation, frustration and/or rejection by (nursing) staff, other residents and/or visitors, which would undermine their willingness to fulfill the resident's needs. Only items that were selected by at least 2 of the experts were included in the next step. Next, frequency distributions of these items were studied in a group of nursing home patients with Alzheimer's disease, a group with other dementias, a group without dementia, and in the total group. If an item was scored with a very low frequency in one or more of these groups (below 10%), it was considered to be non-discriminative, and was therefore discarded. Subsequently, an

MDS-dataset was used for analysis of internal consistency and for exploratory factor analysis, to study the possibility of developing subscales for 'behavioral dimensions'. The dataset from which the challenging behavior scale was constructed consisted of a MDS 2.0 assessment for all 656 residents of four nursing homes in the Netherlands, assessed between September 2002 and April 2003. The mean age was 81. Of these, 74% were women, 71% suffered from moderate to severe cognitive problems (CPS-score > 2).

Results

Step 1. The items that were selected by two or more of the experts were: periods of restlessness (B5d); negative statements (E1a); repetitive questions (E1b); repetitive verbalizations (E1c); repetitive persistent anger with self or others (E1d); recurrent statements that something terrible is about to happen (E1g); repetitive health complaints (E1h); repetitive anxious complaints/concerns (E1i); repetitive physical movements (E1n); withdrawal from activities of interest (E1o); reduced social interaction (E1p); wandering (E4aa); verbally abusive behaviors (E4ba); physically abusive behaviors (E4ca); resists care (E4ea); covert/open conflict with or repeated criticism of staff (F2a); unhappy with roommate (F2b); unhappy with residents other than roommate (F2c); and openly expresses conflict/anger with family/friends (F2d).

Step 2. The following items were scored with a frequency below 10% and therefore excluded: E1g, F2b, F2c & F2d.

Step 3. The results of the internal consistency analysis and factor analysis are presented in Table 1. Cronbach's alpha (Cronbach 1951) of the 15 items was .81, and all items contributed sufficiently to the scale. Principal component analysis revealed one component that explained 28% of the variance, and three additional components that had an eigenvalue above 1. Together, these explained an additional 32% of the variance (60% total variance explained by 4 components). Principal component analyses with these four factors and varimax rotation revealed four sub-scales with meaningful content. They were named Conflict, Withdrawal, Restlessness and Repetition, and Claiming. One item, item E1d (repetitive persistent anger with self or others), loaded considerably on two factors (see Table 1). Although item E1o, E1p and E4aa loaded below .400 on the first component (.392, .398, & .348 respectively), after varimax rotation they appeared important for 'their' factor. Subsequent internal consistency analyses of the sub-scales revealed alpha's ranging from .67 to .80.

The items of two of the sub-scales have different response categories. To calculate sub-scale-scores the items from section E4 were recoded (four response categories on frequency of occurrence). The second and third category of these were recoded into one category, so that they correspond better with the E1 items (which have three response categories on frequency of occurrence). Item B5d (3 response categories concerning presence and onset) was recoded into present/absent. Just as for item F2a, the presence of behavior results now in a score of 1. This means that on the E-items a resident can attain a higher score than B5 and F2a.

After recoding, the 5-item sub-scale Conflict had a range of 0-9; the 2-item Withdrawal a range of 0-4; the 3-item Restless & Repetitive a range of 0-5; and the 5-item Claiming a range of 0-10.

All sub-scales were very positively skewed. The medians of the Conflict and Withdrawal sub-scales were 0, the medians of the Restless & Repetitive and Claiming sub-scales 1. The corresponding means were 1.2, .90, 1.2 and 1.8, respectively.

Table 1: Internal Consistency and Factor structure of challenging behavior sub-scales in nursing home residents (n=656)

Dimension	**Item**	**Description**	**Alpha**	**Factor Analyses**				
				PCA	PCA with varimax rotation			
Conflict	E1d	Repetitive persistent anger with self or others		.718	.471	**.588**	.141	.100
	E4ba	Verbally abusive behaviors		.660	.252	**.652**	.315	~0
	E4ca	Physically abusive behaviors	.68	.448	~0	**.667**	.372	-.144
	E4ea	Resists care		.459	~0	**.678**	.116	.191
	F2a	Conflict with or repeated criticism of staff		.417	.212	**.584**	-.190	.180
Withdrawal	E1o	Withdrawal from activities of interest	.80	.392	~0	~0	.131	**.875**
	E1p	Reduced social interaction		.398	~0	.122	.209	**.862**
R & R[1]	B5d	Periods of restlessness		.586	.290	.130	**.642**	.110
	E1n	Repetitive physical movements	.67	.528	.109	~0	**.791**	.183
	E4aa	Wandering		.348	-.104	.145	**.642**	.127
Claiming	E1a	Negative statements		.652	**.619**	.429	~0	.155
	E1b	Repetitive questions		.609	**.713**	~0	.343	~0
	E1c	Repetitive verbalizations	.76	.611	**.596**	.114	.404	~0
	E1h	Repetitive health complaints		.429	**.700**	~0	-.138	~0
	E1i	Repetitive anxious complaints and/or concerns		.567	**.784**	~0	~0	~0
Overall			.81					

[1]Restlessness & repetition

Although the sub-scales will have the most clinical relevance when they are calculated separately and considered as a behavioral profile, the scores can also be summated because the items form one overall (principal) component and an internally consistent overall scale. The total score can be used as a basic indicator of the presence of challenging behavior. The sub-scales have different ranges, and as a consequence, they contribute with varying strength to the overall scale. However, given the focus of the overall scale, i.e. screening for the presence of challenging behavior, it was decided to simply summate the residents' scores on all 15 items. On this challenging behavior scale, which had a range of 0 to 22 in our sample (with a theoretical

maximum of 28), 82% of all residents had a score above zero, 50% had a score of 4 or higher, and 25% had a score of 8 or higher.

Validity

A second, independent, dataset was used to study reliability and validity of the challenging behavior scale and its sub-scales. Dual assessments enabled calculation of inter-rater reliability of the items and the scales. Validity was studied by determining the (sub-) scales' correlation with each other (hypothesis 1) and with other behavioral scales of the same concepts (hypothesis 2), and by determining whether the scale and its sub-scales correlated as expected with cognition (hypothesis 3). Lastly, the feasibility of our approach was studied (hypothesis 4), by studying whether the scales indeed correlated to social well-being. The following hypotheses were formulated:

1) The four new sub-scales are significantly positively correlated to each other, as they are part of the same construct, but not so high, as they do not measure the same dimension of the construct.
2) Each new sub-scale is coupled with a corresponding measure. The correlations of these two will be higher than the correlations of each of these scales to the other (sub-) scales.
3) As challenging behavior increases with greater cognitive impairment (Beck et al., 1998), a positive relationship must exist between the (sub-) scales and cognitive deterioration as measured by the MDS-CPS.
4) All (sub-) scales are negatively correlated to social well-being as measured according to the MDS-ISE, a scale measuring social engagement, because challenging behavior will undermine others' willingness to fulfill residents' social well-being needs and therefore lead to lower levels of social wellbeing.

Methods

Instruments

The new challenging behavior scale, the Challenging Behavior Profile (CBP) was validated against the Behavior Rating Scale for Psychogeriatric Inpatients (GIP), an observational behavior scale that is widely used and of known reliability and validity in Dutch long term care facilities (Verstraten 1988, de Jonghe et al. 1994). The GIP addresses social, cognitive, psychomotor and emotional behavior in elderly residents, and as the Dutch GIP scale is not yet very well known internationally, we will here summarize its psychometric properties. Just as the newly developed CBP, all five GIP scales addressed in this paper are positively skewed.

The 5-item GIP-non compliant behavior measures behavior regarding resistance against daily routine or certain persons in the environment. The 8-item GIP-socially withdrawn behavior measures the absence of behavior directed towards others, and/or avoidance of interaction with others. The 5-item GIP-restless behavior measures wandering, not being able to sit still, and nervousness. The 5-item GIP-repetitive behavior scale measures behavior that is described as

repetitive movements or vocalizations that do not have an apparent function. The 5-item GIP-dependent behavior measures asking for help or advice very often and trying to attract attention.

When first published, internal consistency (Cronbach's alpha) of these five GIP-scales was .61; .83; .68; .72; .67, respectively, and the inter-rater reliability (Pearson's r) was .68; .79; .75; .71; .72 respectively (Verstraten & van Eekelen 1987). In a validation study, internal consistency was .78; .84; .77; .72; .80, and average inter-rater reliability of the items (Cohen's weighted kappa) was .31; .45; .44; .56; .41, respectively. The internal consistency in this sample was .68; .87; .69; .79; .61. The correlation of the GIP-non compliant behavior scale with the NOSIE-30 sub-scale Irritability was .59 ($p<0.001$), and correlations of the GIP-socially withdrawn behavior with the NOSIE-30 sub-scales 'Social competence' and 'Social interest' were -.43 and -.81 ($p<0.001$) respectively (de Jonghe et al. 1994).

Social engagement was measured according to the Index for Social Engagement (ISE) (Mor et al. 1995). The ISE is a 6-item observational scale that rates the resident's ability to take advantage of opportunities for social interaction and to initiate actions that engage her in the life of the home. The scores range from 0 to 6, with higher values representing more social engagement. Its internal consistency in this sample was .68.

Cognition was measured according to the Cognitive Performance Scale (CPS), which is a 6-item hierarchical observational scale that rates cognitive impairment, with scores ranging from 0 (intact) to 6 (very severe impairment) (Morris et al. 1994). The CPS is scored according to a decision tree. Its reliability and validity have been demonstrated (Morris et al. 1994, Gruber-Baldini et al. 2000, Hartmaier et al. 1995). Its Cronbach's alpha in this sample was .74.

Statistical analyses

For this second sample, inter-rater kappa values of the items (Cohen 1968; Landis & Koch 1975) and intra-class correlation coefficients of the scale-scores (Shrout & Fleiss 1979) were calculated to determine inter-rater reliability. The Landis and Koch classification (1975) was used to interpret both the kappa results and the ICC coefficients (Montgomery et al. 2002) (.00 - .20 = slight, .21- .40 = fair, .41 - .60 = moderate, .61 - .80 = substantial, and .81 – 1.0 = almost perfect). Internal consistency was calculated by Cronbach's alpha (Cronbach 1951). Cronbach's alpha is considered to be good if higher than .70, but should not be higher than .90 (Streiner & Norman 1995). Principal component analysis was done to establish whether the scale's items have one underlying component, and principal axis factoring to provide insight into whether the four identified behavioral dimensions could be confirmed in this second sample. Validity was determined by testing the formulated hypotheses by calculating Spearman's correlation coefficients of the (sub-) scale-scores.

Results

Sample description

For the second analyses, a data set was used that consists of MDS-assessments of 227 nursing home residents. Dual assessments by a second rater were available for 151 residents. 211 to 218 complete GIP-scales were available. The mean age of the 227 residents was 79.9 (52-100), 78% were female, and 54% suffered from moderate to severe cognitive problems (CPS-score > 2).

Reliability

Table 2 shows the results on reliability estimates in the second sample. With the exception of Conflict, the sub-scales appeared to be sufficiently internally consistent in the second sample. Their squared weighted kappa's were satisfactory, with only one item (E4ea: resisting care) having a kappa value below .4. The intra-class correlation coefficient was never below moderate, although the ICC of Conflict and Withdrawal were somewhat low and the 95% confidence interval of Withdrawal included .35.

Table 2: Reliability of challenging behavior (sub-) scales in the second sample of nursing home patients (n=227)

(sub-) scale (N_{range}: 224-226)			**Internal Consistency** (N_{range}: 197-226)	**Inter-rater reliability**			
				Items Kappa (N_{range}: 147-151)		**Scale** ICC[1] (N_{range}: 147-149)	
	N_{Items}	Range	Alpha	Mean K.	Range	ICC	CI 95%[2]
Conflict	5	0-6	.53	.49	.34-.70	.59	.47-.68
Withdrawal	2	0-4	.78	.44	.44-.44	.48	.35-.59
R & R[3]	3	0-5	.66	.65	.57-.71	.80	.73-.85
Claiming	5	0-9	.75	.53	.43-.62	.68	.58-.76
Overall CBP	15	0-19	.78	.53	.34-.71	.75	.67-.81

[1]ICC: Intraclass Correlation Coefficient

[2]CI 95%: 95% confidence interval intra-class correlation coefficient

[3]Restlessness & Repetition

The factor structure was not as strong as in the first sample. In principal component-analysis, the 15 items did all load on the first factor with an eigenvalue of 4.03, explaining 27% of the variance with loadings from .21 to .71. However, five items had a loading below .400 (E1n, E4aa, E4ca, E4ea & F2a). To investigate whether the four sub-scales would emerge when rotating the factor-solution, we used principal axis factoring with the four identified dimensions and varimax rotation. The Withdrawal and Restless & Repetitive behavior sub-scales emerged with loadings ranging from .611 to .801, and .464 to .855 respectively. The items of the Claiming sub-scale loaded on one factor with loadings from .468 to .746, but it was difficult to distinguish the Conflict behavior sub-scale from the Claiming sub-scale. Whereas in the first sample only item E1d of the Conflict sub-scale loaded above .400 on the claiming factor, in the second sample E4ba and F2a also loaded on the claiming factor. Moreover, F2a did not load on the conflict factor.

Table 3: Factor analyses on the second (validation) sample

Dimension	Item	Description	Factor Analyses				
			PCA	PAF with varimax rotation			
Conflict	E1d	Repetitive persistent anger with self or others	.707	.636	.126	~0	**.348**
	E4ba	Verbally abusive behaviors	.559	.488	.104	~0	**.241**
	E4ca	Physically abusive behaviors	.209	~0	.179	.106	**.251**
	E4ea	Resists care	.255	~0	~0	.104	**.634**
	F2a	Conflict with or repeated criticism of staff	.340	.459	-.143	~0	**~0**
Withdrawal	E1o	Withdrawal from activities of interest	.503	.136	.222	**.801**	~0
	E1p	Reduced social interaction	.521	.172	.102	**.611**	.350
R & R[1]	B5d	Periods of restlessness	.554	.326	**.469**	~0	.202
	E1n	Repetitive physical movements	.370	~0	**.855**	~0	~0
	E4aa	Wandering	.211	~0	**.464**	.202	~0
Claiming	E1a	Negative statements	.683	**.746**	~0	.130	~0
	E1b	Repetitive questions	.685	**.567**	.279	.182	~0
	E1c	Repetitive verbalizations	.699	**.594**	.127	.132	.248
	E1h	Repetitive health complaints	.563	**.496**	~0	.299	~0
	E1i	Repetitive anxious complaints/concerns	.487	**.468**	~0	~0	~0

[1]Restlessness & Repetition

Validity

Validity was assessed by testing the four hypotheses described earlier. Table 4 presents the results.

Hypothesis 1: The new sub-scales were significantly correlated to each other, but not very high (range .30- .49). This suggests they measure different constructs indeed.

Hypothesis 2: The associations of the new sub-scales with the GIP-scales were optimal with their corresponding sub-scale (-s), as stated in the hypothesis. Each new sub-scale was correlated higher with its corresponding GIP-scale (-s) than the other new sub-scales were (read the Table horizontally). In addition, each GIP-scale was correlated higher with his corresponding new sub-scale than the other GIP-scales were (read the Table vertically), with the exception of one: GIP-dependent behavior correlated about the same to the new Claiming sub-scale as GIP-restless behavior did (.23 & .24 respectively). The correlations of the GIP scales with the overall CBP suggested that the CBP correspond most to GIP-non-compliant behavior.

Hypothesis 3: Apart from Claiming, the overall CBP and its sub-scales correlated positively to cognitive problems, thus: with increasing cognitive problems, challenging behavior increased.

Hypothesis 4: As expected, the overall CBP and its four sub-scales correlated negatively to social engagement. Withdrawal, which in its content is more or less the opposite of social engagement, correlated the highest (-.57), and Claiming the lowest (-.21).

Table 4: Spearman correlation coefficients of the measures considered in the hypotheses (N_{range}: 208-226)

Hypo-thesis	Measure :	Conflict	Withdrawal	R & R[1]	Claiming	Overall CBP
1	**Withdrawal**	.33**				
	Restlessness & Repetition	.34**	.30**			
	Claiming	.49**	.29**	.30**		
	Overall CBP	.72**	.61**	.69**	.72**	
2	**GIP-Noncompliant behavior**	**.53****	.34**	.37**	.23**	.49**
	GIP-Socially withdrawn behavior	.24**	**.35****	.25**	-.01	.30**
	GIP-Restless behavior	.28**	.09	**.49****	.24**	.39**
	GIP-Repetitive behavior	.32**	.25**	**.47****	.17*	.40**
	GIP-Dependent behavior	.10	.02	-.08	**.23****	.09
3	**CPS**	.22**	.33**	.50**	.08	.42**
4	**ISE**	-.34**	-.57**	-.29**	-.21**	-.48**

[1]Restless & Repetitive behavior

Discussion

In this study, we constructed a reliable and valid behavioral scale, the Challenging Behavior Profile, which is available for all long-term care facilities using the MDS of the Resident Assessment Instrument. This scale is designed for better management of challenging behavior in long term care. It consists of four sub-scales, measuring the behavioral dimensions Conflict behavior, Withdrawal, Restless & Repetitive behavior, and Claiming behavior. The (sub-) scales were found to relate significantly to other scales measuring the same constructs, and an increase in cognitive problems corresponds with more challenging behavior. Although the sum score on challenging behavior is higher in cognitively impaired residents, additional analyses showed that the strength of the correlations with the comparison scales was about the same for residents with and without dementia. This suggests their use in the entire nursing home population.

The relationships of the new (sub-) scales to social engagement are an indication that challenging behavior does impact social well-being, which is in agreement with the ideas of the SPF theory as explained in the introduction. Other researchers in the field do acknowledge that challenging behavior has an impact on the resident's well-being (e.g. Cohen-Mansfield et al. 1989), but they do not explain how challenging behavior impacts well-being. This approach to challenging behavior will let nursing staff and other caregivers understand better why it is an important threat to the residents' well-being, why it is important to measure this behavior, and also, that their own behavior can play an important role in limiting the effect of the behavior on social well-being. They can, for instance, be trained to continue meeting the residents' needs independent from resident behavior. By starting from the viewpoint that challenging behavior primarily has to do with well-being, and by only using behavioral items, we were able to systematically select items and distinguish scales based on meaningful (behavioral) content, instead of using a categorization based on, for instance, physical versus verbal behaviors (Cohen-Mansfield & Billig 1989, Beck et al. 1998).

Although the sub-scales were easily distinguishable in the first sample, internal consistency and factor analyses in the second sample showed less distinct relationships between the items. In the second sample, the Conflict sub-scale was difficult to distinguish from the Claiming sub-scale and had a low alpha. However, a check of the internal consistency of the sub-scales on the 151 MDS-assessments of the second raters that were used for kappa and ICC calculation, revealed an alpha of Conflict of .68 (and of .82 for Withdrawal; .70 for Restlessness & Repetition, .75 for Claiming and .82 for the overall CBP). Also, the factor structure of the second assessments was stronger (only item E4aa loaded below .40 on the first factor, and the Conflict and Claiming sub-scales were better discernable), although item F2a (conflict with or repeated criticism of staff) still did not load on the conflict-dimension. Further research on different samples should therefore study the appropriateness of using item F2a in the Conflict sub-scale and confirm whether the Conflict can be held separable from the Claiming sub-scale.

In contrast with the other three sub-scales, Claiming did not relate to the CPS (cognition). This may be attributable to the fact that these behaviors are also considered as indicators of depression, and thus may frequently be scored by residents without cognitive impairment. Another noteworthy finding is that the GIP-dependent behavior scale did not have strong relationships with the new (sub-) scales. This may have been caused by the low internal consistency of the GIP-dependent behavior (alpha of .61), which may also explain why the new Claiming sub-scale did not correlate obviously stronger with the GIP-dependent behavior scale than with the other GIP-scales.

A limitation of our study may be that by using the MDS as a starting point, although we created a broad range of behavior, it is not ruled out that we have missed some behavioral features, such as suspicious behavior. Further research should therefore include other, non-MDS, items. Notwithstanding, one great advantage of using MDS items for a behavior scale is that thousands of long term care facilities could have instant access to a specific profile of challenging behavior of their residents that requires no additional collection of data. If followed by adequate

interventions, this can have a large positive impact on the quality of life of residents of nursing homes worldwide.

Our approach focuses primarily on the social wellbeing of the resident. Nonetheless, the people around the resident are burdened by challenging behavior as well. A necessary following step is therefore to develop a means to determine whether the challenging behavior of an individual resident is experienced as a problem by the involved (nursing) staff, other residents or visitors. The importance of this step has already been recognized in challenging behavior research, for instance in the Neuro-Psychiatric Inventory of Cummings et al. (1994, 1997). Separate from the threat to the resident's well-being, this can in itself be a valid reason to intervene in challenging behavior. Yet, such interventions may also focus on the people around the resident instead of on the resident.

In conclusion, we successfully developed a measurement scale for challenging behavior (the CBP), which showed to be reliable and valid. This approach to challenging behavior may be the basis of a new method for the clinical management of challenging behavior in long term care, and the scale we constructed may be especially useful as it is easily accessible for many long term care facilities. The impact of challenging behavior on both caregiver distress and resident well-being makes the CBP and its sub-scales an important contributor to the suite of clinical MDS-scales.

PART II:

QUALITY OF CARE AFTER IMPLEMENTATION OF THE MDS-RAI

Chapter 4
Review on the effects of implementation of the MDS-RAI *

* published as:
Achterberg WP, van Campen CC, Pot AM, Kerkstra A, Ribbe MW. Effects of the resident assessment instrument on care process and health outcomes: a review of the literature. Scand J Rehab Med 31:131-137, 1999

Abstract

The objective of the paper is to review the effects of the implementation of the Resident Assessment Instrument (RAI) on process measures (quality of care plans and staff satisfaction) and outcome measures (health problems and quality of life) in nursing homes. All available publications on the effects of the RAI were included in the review. The most positive effects of the RAI were found in the improvement of the comprehensiveness and the accuracy of the care plans. As regards outcome quality, the RAI method had most positive effects on the health condition of nursing home residents with diminished physical and mental functioning. In psychosocial areas of assessment, fewer positive effects were found. We concluded that positive effects have been found, based on pre-test-post-test non-controlled designs. Control-group designs are needed in future evaluation studies to determine if these positive results will hold.

Introduction

The Resident Assessment Instrument (RAI) was originally developed in the United States in response to poor quality nursing home care that gave rise to public concern (Morris et al. 1990). In 1986 the Institute of Medicine reported on the quality of care in nursing homes. To improve the quality, the need for a uniform assessment instrument was identified as a key component (Institute of Medicine 1986). In 1987, the US Congress mandated the use of a comprehensive validated assessment instrument for nursing homes as part of the Omnibus Budget Reconciliation Act (OBRA '87). The Health Care Financing Administration contracted a research consortium to design the system, which is now known as the *Resident Assessment Instrument* (RAI)((Hawes et al. 1997).

The RAI describes a nursing home resident on multiple domains of function and is derived from caregiver observations (see Appendix). These data (the Minimum Data Set or MDS) can identify ("trigger") potential problems in 18 different areas. Special Resident Assessment Protocols (RAPs) have been designed for each of these areas. These RAPs provide directional aids for the analysis and optimal management of each problem. The MDS, triggers and RAPs lead to individual care plans formulated on the basis of a structured assessment (Morris et al. 1991, Morris et al. 1995).

The contribution of the RAI to quality assurance and improvement is expected on the basis of the following thesis: Patient assessment by means of the RAI will provide more accurate information about patients' needs. Client-tailored care plans will be formulated on the basis of this information (MDS and RAPs), which will diminish the gap between patients' needs and the care provided, and, consequently, quality of care will be improved. In this article, the effects of implementation of the RAI in nursing homes are subdivided into process measures (effects on quality of the care process) and outcome measures (effects on health and quality of life) (Donabedian 1985, Ovretveit 1992).

The objective of this article is to review evaluation studies on the effects of the RAI on process and outcome measures of quality of care. The research question is: What are the effects of the RAI on: a) process measures (the quality of care plans and staff satisfaction), and b) the outcome measures of health problems and patient quality of life?

Methods

The databases of Medline, Online-Current Contents, CINAHL and Psychlit were searchedusing the key-words "Resident Assessment Instrument" and "Minimum Data Set". In addition, members of the group working on cross-national implementation of the RAI (interRAI) were asked for manuscripts and work in progress. It is almost certain that all publications evaluating the effects of the RAI on nursing home populations or other elderly populations in long-term care facilities have been covered.

Nine publications were found, three of which concerned the same study (see Table I for methodological characteristics). We will discuss the US and Japanese studies in more depth because of their complexity. In Canada and the European countries, several RAI-evaluation studies are in progress and the first publications are expected in 1999.

Results

The evaluation study in the United States had a longitudinal cohort pre-implementation-post-implementation design, with four waves of data collection: two before implementation (fall 1990 and 6 months later) and two after (spring 1993 and 6 months later) (Fries et al. 1997, Hawes et al. 1997, Hines et al. 1994, Mor et al. 1997, Phillips et al. 194, Phillips et al. 1997). The pre-RAI cohort consisted of 2.170 nursing home residents from 268 institutions in 10 states (the states were carefully selected to minimize bias). The post-RAI implementation cohort included 2.088 patients from 254 (out of the pre-test 268) nursing homes. Specially trained research nurses collected the data. The sample was representative of US nursing homes (Phillips et al. 1994).
In Japan, the evaluation of the RAI implementation was carried out in 15 geriatric hospitals, 7 health facilities for the elderly and 5 special homes for the aged (Ikegami et al. 1998). The facilities were not representative of Japanese long-term care settings. The chosen facilities were selected by the research-group on the basis of high quality. However, even in these facilities implementation was erratic, to the point that 9 facilities had to be excluded from the analysis. Data on the care plans were available from 7 geriatric hospitals, 6 health facilities for the elderly and 5 special homes for the aged. The evaluation consisted of two parts: first, cross-sectional samples from 90 care plans were compared at the time of their introduction with 92 care plans one year later, on the percentage of triggered RAPs addressed; second, 135 care plans at introduction were examined and compared with 147 care plans one year after introduction, using selected standards.

Process measures: Quality of care plans and staff satisfaction

In the US study, the residents' care plans and the facilities' medical records were evaluated for accuracy of information and comprehensiveness of information (number of RAPs addressed in the care plan) (Table I) (Hawes et al. 1997). For each resident in the pre- and post-implementation cohort, data in the medical record collected by specially trained research nurses were compared on 23 critical MDS items. In the post-RAI records, the information on MDS items was more accurate: the percentage of residents which had >90% information accurate increased from 17.6% to 48.6% after RAI implementation. There was also a significant increase in the number of care plans, addressing 12 out of 18 RAP areas: cognitive loss, visual function, communication, ADL rehabilitation, incontinence/catheter, mood state, behaviour, falls, nutritional status, dehydration, dental care and psychotropic drug use. Pressure ulcer was significantly addressed less.

In the same study, other process measures of quality of care were evaluated. In the post-RAI group there were fewer residents' using physical restraints (9.5% decline) and indwelling catheters (29%), and increase in the use of toiletting programs (5.1%), behaviour management programs (5.9%) and hearing aids (9.6%) for those who seemed to need it. There was also an increase in the presence of advanced directives (64%). Changes on the following indicators were not statistically significant: 'preventive skin care', the use of antidepressives or antipsychotics/hypnotics, the number of residents with inadequate vision who did not have glasses, toiletting programs for urine incontinency and residents with mood problems who receive therapy.

In Japan, the evaluation study showed that one year after the implementation of the RAI the following RAPs were at least 10% more frequently addressed in the 90 care plans: falls (13.3%), nutritional status (14.0%) and dental care (10.9%) (Ikegami et al. 1998). Interestingly, a number of psychosocial RAPs were less often addressed: mood state (36.8% less), behaviour problem (27.5% less) and psychosocial well being (12.5% less) (Table I). An improvement in the quality of the contents of the care plans was found with respect to a number of selected standards that were derived from an expert panel: 'relationships between problems taken into account' (21.1% increase), 'specific, individualized contents' (20.3%), 'role of each member of staff' (19.5%), 'future risks, options, prognosis taken into account' (17.1%), 'improving and maintaining ADL and quality of life' (11.1%), and 'enliven daily through activities' (7.4%) (Ikegami et al. 1998).

As a second indicator of process quality, we examined the available studies to determine if the professionals who worked with it appreciated the RAI. Evaluation studies of staff satisfaction have been carried out in the US, where RAI was mandatory. A post-implementation telephone survey assessed the opinions of Directors of Nursing and facility administrators about the RAI (Table I) (Hines et al. 1994, Phillips et al. 1994, Phillips et al. 1996). On the basis of 236 interviews, it was found that 63% of Directors of Nursing said clinical staff had strongly opposed RAI during RAI implementation, and 43% stated staff was still resistant to using the RAI after implementation. Although 68% percent of the administrators thought RAI presented an excessive paperwork burden, 64% said it was worth the time and effort spent by staff. The vast majority of Directors of Nursing thought that the RAI was an improvement compared to the former assessment instrument, that assessment and care planning were qualitatively better and the ability of the staff to assess the functional as well as cognitive status had improved after the implementation of the RAI.

In another study, 191 structured and open interviews were held in 18 nursing homes in 6 states in the US (none of which were involved in the large evaluation study) (Dorman-Marek et al.1996). The sample included 132 professionals (21 administrators, 36 licensed nurses, 18 certified nursing assistants, 15 advocates, 15 professional associations, 27 regulators) and 59 residents (Table I). The interview contained 27 items about the changes in quality of care and quality of life after the OBRA '87 regulations. Ninety-six out of 132 professionals (73%) said the MDS was the most helpful component of OBRA '87. The MDS was described as a tool able to give a 'whole picture' of the resident, allowing nurses to 'know the resident better', and it was seen by

care providers as a practical instrument for providing better care. Of 132 professionals, 86 (65%) stated that working with RAPs improved assessment, analysis and care plans. However, only 10 professionals indicated that it was a 'major improvement'; others were less enthusiastic.

Outcome measures: health problems and quality of life

In the US, the prevalence and changes (improvement or decline) of eight selected health conditions and problems were studied in the evaluation cohort (Fries et al. 1997). Dehydration had a lower prevalence after RAI-implementation (2% pre vs 1% post), and the same applied for 'static ulcers' (which showed a decline from 4.5% to 3%) (Table I). The prevalence of 'daily pain' however had a higher prevalence after implementation (13.4% pre vs 17% post). Significant changes in the prevalence of 'falls', 'malnutrition', 'decubitus', 'vision' and 'poor teeth' were not observed. For 'malnutrition', 'vision', 'falls' and 'decubitus' there were reductions in both the 6-month rate of decline and improvement.

In the large US evaluation study, several quality of life indicators were assessed twice in each of the pre- and post implementation waves (Table I) (Morris et al. 1994, Phillips et al. 1997). Baseline differences for these two groups existed only in the incidence of urinary-incontinence (in the post-RAI cohort there was more incontinence). In this study, the hypothesis was tested that residents in the post-RAI group improved more and declined less on several functions. It was found that in all three functional areas, residents in the post-RAI cohort were less likely to decline, but also less likely to improve. To compare change in decline to change in improvement, estimates were generated of the difference in the number of residents who declined and improved in the pre-RAI and post-RAI cohort. With these estimates, ratios were calculated that compare the change in decline to the change in improvement in the cohorts (table II) (Phillips et al. 1997).

In general, reductions in decline in the post-RAI group outweighted the reductions in improvement. However, for 'understanding others', 'sad mood' and 'unsettled behaviour' the reduction in improvement outweighted the reduction in decline. It should be noted that the changes were not the same for all groups of patients: for example, the residents who scored better on ADL and cognition in particular showed less improvement, and the most impaired residents showed less decline after RAI-implementation.

Analysis of the two cohorts revealed that the RAI had no significant effect on mortality (6.8% vs. 7.5%) or home discharge (1.9 vs. 1.1%) (Table I) (Mor et al. 1997). However, an overall 28% decline in transitions to hospital was noticed. Hospitalization in those with severe cognitive impairment declined from 20.1% to 13.5%. Furthermore, 15.9% of survivors with stable ADLs were hospitalized in 1990 while in 1993 the hospitalisation rate declined to 10.9%. For those who declined in ADL, there was an increase in hospitalization after RAI-implementation from 25.2% in 1990 to 40.6% in 1993 after RAI implementation. These results suggest that there is better selection of residents who will benefit most from hospitalization.

Discussion

The most important effects of the RAI are found in indicators of the care process. The comprehensiveness and the accuracy of the care plans improved, especially in the US. From a methodological point of view one could object that the standard to which these care plans were compared were derived from the MDS items or RAPs. The research into the development and testing of the MDS and RAPs created a standard for quality of care in the US (21). In Japan, improvements were found in the quality of care too. However, these results must be interpreted carefully, because of the selection-bias and drop-out of the participating facilities. In interviews with Directors of Nursing, resistance to the implementation of the RAI was found. This may be related to the fact that the implementation of the RAI was mandatory and that the RAI training programmes offered by the nursing home management differed greatly from one nursing home to another (personal communications).

As regards outcome indicators of care, the implementation of the RAI showed encouraging general effects. The RAI method appears to have the most positive effects on the most impaired residents, since they declined less rapidly in function. Residents who score better on physical and mental functioning improved less after the RAI implementation. This could be due to a statistical ceiling effect. Another explanation could be that there is a shift in care to those who seems to need it most, potentially a result from the RAI's objective to assess patient needs. The overall effects showed a stabilization of the sample, with fewer residents declining and fewer improving.

Positive effects on specific health problems were found, particularly on dehydration and pressure ulcers. An interesting fact was that more daily pain was registered. Perhaps this is because there is no RAP for pain. This result suggests that assessment with the RAI is strongly guided by the other RAPs.

In general, the psychosocial areas of assessment showed few positive effects. Indeed, in the US study three indicators of psychosocial functioning showed a net negative result (Table II). The lower impact of the RAI on psychosocial outcomes deserves more study.

An important positive effect was the decline in hospital admissions in the US and the shift in residents who were hospitalized. This can be attributed partly to a trend in the US towards deaths occuring in the nursing home rather than in hospitals (Bergman et al. 1991, Mor et al. 1997, Sager et al. 1989). However, the increase in the proportion of deaths occurring in nursing homes was small in comparison to the decline in hospitalization. It seems possible that the RAI helped reduce the incidence of serious conditions, or exacerbations of chronic diseases, and may have been helpful in selecting residents who could benefit most from hospitalization.

With regard to the methodological soundness of the evaluation studies, it should be noted that the positive effects found in the US studies were based on a non-controlled design. Although the interrupted time series design (with large representative cohorts) that was used is a powerful approach, without control-groups it is difficult to attribute the observed effects *solely* to the implementation of the RAI. Because the RAI was nationally implemented, a randomized controlled trial was impossible. Furthermore, as one part of a set of regulations (OBRA '87) for

improving the quality of care, one could argue that these regulations highlighted the flaws and were an incentive to provide better care. The research design of the Japanese evaluation study also lacked a control group. With regard to the outcome measures of the RAI-evaluations, some have argued that the perspective of the residents has received little attention in the evaluation studies (Schnelle 1997, Uman 1997).

The lack of randomized controlled trials and the lack of information on residents' experiences has prompted the call for a definitive evaluation study, with control groups, in the Netherlands. This evaluation includes studies on process measures of quality of care plans and staff satisfaction, as well as process and outcome measures of perceived quality of life. For future research, the implementation of the RAI in different countries on different continents provides excellent opportunities. Data sets with identical patient records have become available, since in each country the standardized RAI method is being implemented in a similar manner, a process that is monitored by the interRai group with members in all participating countries (Berg et al. 1997, Carpenter et al. 1997, Fries et al. 1997, Frijters et al. 1997, Ikegami et al. 1997, Ljunggren et al. 1997, Ribbe et al. 1997, Schroll et al. 1997, Sgadari et al 1997). However, international comparisons have their drawbacks. Because of baseline differences (e.g. patient populations, local health policies) and contextual factors (e.g. accreditation, reimbursement, quality assurance) for the implementation of the RAI in the different countries, the impact of the RAI cannot be expected to be internationally consistent, and also needs to be considered in national and local perspective.

Improving quality of care and quality of life in long-term elderly care is a major challenge worldwide, and the implementation of the RAI has shown it to be a very promising scientific and practical instrument for these improvements (Phillips et al. 1996).

Appendix: The Resident Assessment Instrument

The Resident Assessment Instrument is a method for comprehensive functional assessment of nursing home residents, with the object to guide the development of individualized care plans.
RAI consists of :
- a Minimum Data Set (MDS)
- an identification of problem areas
- specific Resident Assessment Protocols (RAPs)
- a user's manual

The MDS is a core of assessment items that provides a comprehensive picture of each resident's functional, cognitive and emotional status and a variety of other areas, including resident's strengths, preferences and needs (see MDS sections in table below). The full MDS assessment is repeated yearly. In addition a quarterly review is done with a subset of MDS assessment items. This review is intended to monitor the resident's response to the care plan and determine whether sufficient change has occurred to trigger a more comprehensive assessment.

Problem areas are identified by applying a set of algorithms to a resident's MDS data, that will suggest problems, risks for development of a problem, or potentials for improved function.

The 18 condition-focused RAPs (see table below) specify additional assessment of identified problem areas in the resident's status. The protocols are intended to more directly link the MDS information to care plan decisions. Facility staff then use the more specialized assessment guidelines found in the RAPs to identify potentially treatable causes and focus decisions about the resident's plan of care and services.
The user's manual provides detailed specifications about how to complete the MDS and RAP assessment process (e.g. interviewing staff, residents and family members, reviewing records) and contains item definitions, examples of coding options and clinical guidelines for using the RAPs to develop care plans.
In the US, the RAI is mandated for all Medicare-Medicaid nursing homes. In Europe, Canada and Japan the RAI has been implemented in the assessment of institutionalized frail elderly on a more voluntary basis. In Japan, RAI is recommended (not mandated) by the Ministry of Health and Welfare for three types of long-term care facilities for the elderly: geriatric hospitals, health facilities for the elderly and special homes for the aged. In several European countries (Iceland, Denmark, Sweden, United Kingdom, France, the Netherlands, Switzerland, Germany and Italy), local initiatives have been taken to start implementation of the RAI in a restricted number of nursing homes. In Iceland, RAI is mandatory and used in all nursing homes.

Table I: Methodological characteristics of effect evaluations of RAI

Study	Design	n	Dependent variable	Measuring instruments	Effects	
					Process	Outcome
Hawes 1997(US)	quasi experimental repeated measure	ca. 2100 patients	- care plans accuracy and comprehensiveness - quality of care process indicators	- analyses of patient charts	- improved accuracy careplans - more comprehensiveness in 12 out of 18 RAPs - improvement on quality indicators	
Fries et al. 1997 (US)	id.	id.	- selected health conditions and problems	- MDS items - RAPs - CPS - ADL		- lower prevalence of dehydration and static ulcera - higher prevalence of pain - less decline & less improvement of vision, nutrition, falls, decubitus
Mor 1997 (US)	id.	id.	- transitions to hospital - mortality - transition to home	- analysis of patient charts		- lower hospitalisation rate - no effect on mortality or home discharge
Phillips et al. 1997 (US)	id.	id.	- 9 physical, mental and social functional area's	- MDS items		- less decline in all but sad/ anxious mood and unsettled behavior
Phillips et al 1994 (US)	posttest	236 DONs	- satisfaction with RAI	- telephone interviews	- resistance to implementation - assessment and care planning qualitatively better - more involvement resident and family	
Dorman-Marek 1996 (US)	posttest	191 (staff and residents)	- staff and residents perceptions of progress since OBRA '87	- structured and open end interviews	- improvement quality of care	
Ikegami 1998 (Japan)	pretest/posttest	18 facilities	- quality of careplans - addressing of RAPs	- analyses of patient charts - MDS	- improvement process quality -4 RAP areas more addressed - 3 RAP areas less addressed	

ADL = activities of daily living, CPS = Cognitive Performance Scale (derived from MDS-items), DON=Director of Nursing, MDS=Minimum Data Set, RAI=Resident Assessment Instrument, RAP=Resident Assessment Protocol

Table II: Effects of RAI on quality of life indicators

Indicator	Difference in decline divided by difference in improvement (in pre-RAI and post-RAI cohort)
Physical functioning	
ADL index	2.02
Bowel incontinence	1.05
Urinary incontinence	1.57
Mental functioning	
Cognitive Performance Scale	1.92
Sad or anxious mood	0.10
Unsettled Behavior Scale	- *
Social functioning	
Social Engagement Scale	1.89
Being understood	0.95
Understanding others	.063

This table is based on the results published by Philips et al. (1997)
Ratio>1 means reductions in decline outweigh the reductions in improvement
* Increase of decline and decrease of improvement, no ratio could be computed

Chapter 5
Quality of co-ordination of nursing care after implementation of the MDS-RAI*

* published as: Achterberg WP, Holtkamp CC, Kerkstra A, Pot AM, Ooms ME, Ribbe MW. Improvements in the quality of co-ordination of nursing care following implementation of the Resident Assessment Instrument in Dutch nursing homes. J Adv Nurs 2001;35(2):268-75.

Summary

The Resident Assessment Instrument (RAI) was designed to improve the quality of care and quality of life in Nursing Homes. Until so far, only non-controlled studies on the effects of implementation of the RAI have been done. We studied the effect of implementation of the Resident Assessment Instrument (RAI) on the quality of co-ordination of nursing care in Dutch nursing homes in intervention wards with RAI compared to wards with no intervention. We used *the co-ordination of nursing care instrument*, which includes measures for case history, care plan, end of shift report, consultation, patient allocation and patient report. The scores on these scales represent the quality of nursing procedures on a ward. The measurements were done one month before and 8 months after RAI-implementation in eighteen wards in ten nursing homes in the Netherlands. Out of 348 somatic patients on the participating wards who met the inclusion criteria and signed an informed consent, 278 could be measured at the first and 218 at the second data collection. Only 175 residents could participate twice.

There were marked differences in baseline scores for co-ordination of nursing care in the experimental and comparison wards. We used a meta-analysis technique to study the mean differences between 8 couples of RAI/control wards before and after the intervention. The mean difference scores showed significant positive improvement in the RAI group for case history, there were minor (not statistically significant) improvements for all other scores and the total score. These results are remarkable because RAI-implementation in all the experimental wards did not proceed according to plan, due to staffing problems.

We conclude that RAI is a useful instrument for improving the quality of co-ordination of care in nursing homes.

Introduction

Nursing homes deliver care to frail, mostly elderly residents. The care needed for these residents is often complex and multidimensional. This includes improving, maintaining or slowing decline in health conditions, physical, cognitive, communicative and psychosocial functioning as well as creating a pleasant living environment. Nurses play a crucial role in the process of achieving these goals, because of the central position they have in the care process.

Quality of care encompasses several dimensions. When evaluating this quality, it is useful to divide it into structural aspects (e.g. staffing and budget), process aspects (e.g. case history, making a care plan) and outcome measures (e.g. health and well-being of a resident) (Donabedian 1982). Co-ordination of care is an aspect of process quality that is supposed to improve the quality of care by providing tailor-made care (van Achterberg et al. 1996). To bring about this tailor-made care, thorough assessment is essential. Taking a case history is an important part of this assessment. But co-ordination of care also includes a qualitative good care plan, good communication between care givers, an efficient patient allocation, patient report and transfer of information from one nursing shift to another (end of shift report).

The Resident Assessment Instrument (RAI) has been developed as an answer to concerns about poor quality of care in nursing homes in the United States. Its goals are improving the quality of care and quality of life in nursing homes (Morris et al. 1990). The RAI consists of a structured screening questionnaire (the Minimum Data Set MDS), an algorithm that links the information from the MDS to certain important problem areas, and protocols (Resident Assessment Protocols, RAPs) for these problem areas.

A nurse fills the MDS out for the majority of items. The MDS has over 300 items concerning many domains of physical, mental and social functions. It requires observations, interviews and clinical assessment. The full MDS is conducted at admission and yearly thereafter, between these full assessments a quarterly review is filled out, which is a condensed version of the full MDS. When a resident has however an important change in health status on another moment, a full MDS assessment has to be done. A full MDS assessment done by an experienced nurse takes about 30 minutes.

Certain scores in the MDS trigger specific protocols, the RAPs. There are 18 RAPs, which give directives for further analysis and handling of major problem areas in nursing home care. The RAI therefore links structured, individual assessment information to care planning of that resident, which should lead to 'tailor-made' care.

Definitions of MDS-items, guidelines to fill out the MDS, the RAPs and practical guidelines for taking a case history, observations and communication between care givers and the making of a care plan are described in the RAI Manual (Morris et al. 1991, Morris et al. 1995).

The effects of implementation of the RAI in nursing home care in the United States have been evaluated in a large longitudinal, quasi-experimental (non-controlled) cohort design. Changes in the care process have been found after implementation, especially improvements in the accuracy and comprehensiveness of care plans and resident documentation. (Hawes et al. 1997a). Besides the number of RAPs that was triggered (comprehensiveness of care plans), a set of 23 MDS-

items was used to study the accuracy of the information in the documentation of the resident. This approach showed that the RAI improved an important aspect of quality of care. However, the evaluation of the accuracy of information in the documentation was derived from MDS-items and the number of RAPs triggered. Therefore the evaluation standard was derived from the intervention. Also, this study lacked comparison groups (Achterberg et al. 1999). Did these findings really prove a better care process, or just compliance with the mandated implementation? In Japan, there have also been changes in the care process after RAI implementation: some problem areas are more frequently, others less frequently addressed in the care plan, and there has been an improvement in the quality of the content of the care plan (Ikegami et al. 1998). Again, this study had no comparison group, and the select group of participating Japanese facilities makes interpretation of these results unclear. Following the implementation of the RAI in the USA, nursing homes in other countries like Japan, Canada and several European countries have decided to use the RAI (Hawes et al. 1997b). In Sweden, implementation of the RAI has also lead to increased nursing documentation: more residents had care plans and there were more daily notes on important resident situations, again in a non-controlled design (Hansebo et al. 1999).

In the Netherlands, there are 325 nursing homes with 53.800 beds (26 per 1000 elderly people) (Ribbe et al. 1997). Fourteen nursing homes have recently started implementation of the RAI. To gain more insight in the effects of the RAI on the care process we conducted a controlled trial, with the following research question: Does the implementation of the RAI method improve the quality of the co-ordination of care in Dutch nursing homes?

An instrument for measuring quality of nursing care in Dutch nursing homes has been developed and validated which focuses on three aspects: co-ordination of care, instrumental/technical aspects and environmental/living aspects (van Lingen et al. 1990). Co-ordination of care is here divided into six main quality aspects: taking case history at admission, content of the care plan, end of shift report, communication (between nurses and other caregivers and patient), patient allocation and content of patient report. These aspects are strongly related to procedures at ward or facility level, and therefore these scores are an indication of the quality of co-ordination of care at the ward/facility level.

Considering these quality aspects and the procedures described in the RAI method, we expect to see improvements after RAI-implementation in the quality of taking a case history, the care plan, patient report and communication. The RAI gives no directions for the end of shift report and patient allocation and we therefore expect no influence on these items.

Methods

Design and sample

The study employed a non-randomized, controlled trial. Nursing homes that planned to implement the RAI were asked to participate.

Data were collected through site visits in 9 somatic wards in 7 nursing homes, which planned to implement the RAI. Comparison wards were recruited from the same nursing home (in four nursing homes, where RAI-implementation was planned to be phased in) or comparable other 'matched' nursing homes; two nursing homes could only include experimental wards and were matched with four nursing homes. For this matching, a questionnaire was used which contained 40 items about facility characteristics, organization and care services.

Inclusion criteria:

- Admitted for long term care at a somatic ward with an expected remaining duration of stay longer than 9 months
- Able to understand simple questions and to answer yes or no verbally by pointing at the intended answer
- Able to give informed consent according to the judgment of the investigator

Exclusion criteria:

Psychogeriatric residents, residents with terminal illness and residents who were admitted for rehabilitation were therefore excluded.

Specially trained research staff conducted structured interviews with residents (who had signed an informed consent) and studied these residents' care documentation. When residents could not participate in the interview because of fatic or cognitive disorders, their family members were asked to complete a questionnaire. On each ward, several nurses were asked to complete a structured questionnaire.

Data collection took place 1 month before and 8 months after RAI-implementation.

Data were collected for 21 nursing home wards with 348 residents in the pre-RAI cohort. Interviews with the resident could be held in 278 cases in the first data collection round, and with 218 residents in the second round (table 1). A total of 175 residents, 61 men and 114 women participated in both the pre and post measurements. The average age was 78.6 years.

In the participating wards, drop out after the first measurement ranged between 0 and 63.6% (table 2). The reasons for this longitudinal attrition and non-response are described in table 3.

Table 1: Distribution of residents who participated in none, one or two data collections after inclusion.

	pre test interview	Pre test interview +	
Post test interview -	27	103	130
Post test interview +	43	175	218
Total	70	278	348

Table 2: Reasons non-respons and longitudinal attrition after inclusion for data collection.

Included	**348**	**Reasons non-respons/drop out**
No pre test data collection	27	5-death 4-too ill 7-refusal to participate 6-non-respons family
Pre test data collection done, but no posttest data collection	103	62-death 11-too ill 12-refusal 10-non-respons family 8- other
Total residents who participated in pre and post test data collecion	175	
Newly included in post measurements	43	

A relative large number of participants dropped out during the study because they deceased (n=62) or were too ill (n=11) to answer the questions in the second interview. Other reasons for dropout in the post measurements of the approached residents were: refusals (n=12), non-response by family members (n=10), transfer to another ward (n=4), discharge (n=2) and other reasons (n=5) (see table 3).

Intervention

A nursing home that planned to implement the RAI started with a workshop about RAI and formed a project group that was trained in the RAI method. Training consisted of a 4-day course. This training was identical for all participating nursing homes. The trained project group was responsible for further training of caregivers and implementation of the RAI in the nursing

home. The way this training and implementation was carried out was basically the same, but could differ on details. Some nursing homes choose to carry out the implementation in phases, while others choose to implement it in a single effort. Feedback on the MDS outcomes such as quality indicators and case-mix was not available in the studied period of time for the RAI-wards.

Table 3: Experimental (E1-E8) and control (C1-C8) wards: total number of participants in pre and post measurement and number of residents in wards who participated twice (321 residents participated, 146 once and 175 twice).

RAI ward	**n pre**	**n post**	**n pre & post**	**% drop out after pre-measurement**	**Control**	**n pre**	**n post**	**n pre & post**	**% drop out**
E1	22	19	15	31.8%	C1	11	8	7	36.4%
E2	17	22	17	0%	C2	32	27	23	28.1%
E3	36	23	18	50%	C3	21	14	14	33.3%
E4	11	11	11	0%	C4	6	8	6	0%
E5	8	5	5	37.5%	C5	11	6	4	63.6%
E6	15	11	8	46.7%	C6	11	11	6	45.5%
E7	7	7	5	28.6%	C7	8	3	3	62.5%
E8	27	17	13	51.9%	C8	10	7	7	30%
					C9*	25	19	13	48%
Total	143	115	92	35.7%		135	103	83	38.5%

*this nursing home was supposed to have an experimental and control ward, but it did not implement the RAI and was therefore not included in the analysis)

Measuring instruments

Dependent variables

The process quality was assessed by means of the subscale "co-ordination of care", a part of the "Quality of Nursing Care in Nursing Homes instrument", developed by van Lingen et al. (1990). It measures the judgment of residents and nurses on the process of co-ordination of care, including the care plan. It contains several structured questions for residents (interviews) and nurses (questionnaires) and information found in the residents care documentation on the following aspects (subsets): case history, the care plan, patient report, end of shift report, communication and allocation of nurses to residents. The instrument consists of quality standards and accompanying criteria, which are discrete items of practice, which are observable and measurable. Examples of quality standards concerning all six aspects of co-ordination of care are shown in table 4.

In the total score all aspects are equally weighted. All scores were recalculated to create a scale from 0 (the worst possible score) to 100 (the best possible score). Acceptable content validity

has been shown with the Delphi method by van Lingen et al (1990), interrater reliability for co-ordination of care was good (Cohen's kappa 0.73).

Procedure

Data collection took place in a fixed order. First, residents were interviewed individually and face-to-face (the resident part of the co-ordination of care scale). Second, the primary nurses of the participants were asked to complete a questionnaire with the nurse's part of the scale. Finally, the research-assistants analyzed the care records of the participating residents.

Table 4: The instrument by Van Lingen et al. to measure quality of co-ordination of care: standards and criteria.

Aspect of the co-ordination of care instrument	Number of standards	Number of criteria	Maximum points	Example of a quality standard
1-Taking case history	4	6	12	Case history has to be done within 24 hours after admission in nursing home, together with resident and family
2-Care plan	7	15	30	In the care plan the level and kind of self care activities of the resident has to be recorded
3-End of shift report	4	4	8	The end of shift report has to be in writing and explained verbally by the nurse
4-Communication	6	11	22	At least once a week a number of nurses have to discuss and evaluate if the nursing care takes place according to the care plan
5-Patient allocation	2	2	4	No more than two nurses should be responsible for the different aspects of care of a resident during a shift
6-Patient report	5	6	12	Residents health status has to be recorded according to the instructions

Analysis

Co-ordination of nursing care is a nursing home and ward specific measure, not a resident specific measure. It provides information on aspects of procedures, which are custom in that nursing home or ward. Approaching the data on resident level with ANOVA would exclude those who died or were too ill after the first data collection, and those who were newly admitted. It could also bias the results, because the number of residents in the separate wards was very different. Multilevel analysis can be used to look at individual as well as ward level, but also uses paired samples and would exclude those who only participated in one data collection round.

Therefore we decided to analyze primarily at ward level, and to approach the data of the experimental/control couples as if they were Randomized Clinical Trials pooled in a Meta-analysis (Whitehead & Whitehead, 1991). Mean scores (and SD) were calculated on ward level. Mean differences (mean post- mean pre) of the experimental and control wards were used to make 8 couples (experimental versus control) of mean differences. These standardized mean difference then were pooled to create a standardized mean difference with 95% confidence interval. In this analysis, participants who completed at least one data collection could be analyzed.

Results

The overall mean score on the co-ordination of care in the pre-RAI cohort was 53.9 (%), with the lowest mean score on the care plan (47.1), and the highest on 'end of shift report' (72.6). The mean scores for the ten participating nursing homes for the total co-ordination of care ranged from 46.7 to 63.5 ($p < .0001$), for the participating wards from 45.45 to 64.98 ($p < .0001$). Mean baseline scores for the intervention and control residents did not differ significantly for care plan, communication and patient allocation, but they were significantly higher in the comparison group for taking case history, end of shift report and the total co-ordination of care score; patient report score was significantly higher in the intervention group.

Table 5: Baseline scores on co-ordination of nursing care in the control and intervention group.

	Intervention group (n=143) Mean (sd)	**Control group (n=135) Mean (sd)**	**P**
Taking case history	49.1 (15.7)	60.1 (17.0)	***
Care plan	47.1 (10.6)	46.4 (12.5)	
End of shift report	70.2 (19.2)	77.8 (19.6)	**
Communication	53.7 (21.1)	57.1 (19.6)	
Patient allocation	82.6 (23.9)	86.3 (22.4)	
Patient report	71.2 (8.2)	67.9 (9.0)	**
Co-ordination total	52.8 (8.7)	55.5 (9.4)	*

*p< .05; ** p< .005; *** p< .001

One of the intervention wards did not implement the RAI because of staffing problems, and was not included in our analysis. The 8 intervention wards with the 8 matched controls had 253 residents in the first data collection, in the second data collection 199 residents.

All pooled mean differences showed heterogeneity of the mean differences, therefore we decided to use a random effect approach. Pooled mean differences for Case history showed a significant positive effect for the wards which implemented the RAI compared to their control

wards (U=6,11; Q=59.89, p<0,05) The (random) effect-size was 6.5 (95% CI: 1.35, 11.73). For all other subscales a positive, but not significant effect was found. Random effect for Care plan was 0.8 (-2.49, 4.06), for End of shift report 0.1 (95% CI: -1.27,1.5), for Communication 4,2 (95% CI: -8.56, 16.94), for patient allocation 6.0 (95% CI: -6.98, 18.93) and for Patient report 1.3 (95% CI: -3.17, 5.74). For the total co-ordination the random effect was 2.8 (95% CI: -0.28, 5.82).

At the end of the data collection, a semi-open interview with the nurse in charge of the ward was held to find out whether there had been any kind of problems with the intervention, i.e. the implementation of the RAI. In these interviews it appeared one nursing home had not yet implemented the RAI at all at the ward that was designated (and where the pre-test data collection had already taken place) because of staffing problems. In all intervention wards problems with staffing (caused by sickness and mutation of staff) or availability of a satisfactory software package resulted in a delayed or adapted (less complete) implementation effort. This meant that fewer MDS-forms were filled out, and that the analysis of the identified RAPs hardly ever occurred. In the comparison group all wards also faced staffing problems.

Table 6: Pooled mean differences (pre and post intervention measurement) of 8 intervention/control couples of nursing home wards on items of the coordination of care scale.

	Mean difference#	**95% Confidence Interval**	**p**
Case history	6.5	1.35, 11.73	*
Care plan	0.8	-2.49, 4.06	
End of shift report	0.1	-1.27,1.5	
Communication	4.2	-8.56, 16.94	
Patient allocation	6.0	-6.98, 18.93	
Patient report	1.3	-3.17, 5.74	
total co-ordination	2.8	-0.28, 5.82	

positive mean difference means better for intervention ward then for control ward
*p< 0,05

Discussion

Dutch nursing home wards show large differences in the quality of co-ordination of nursing care, an important aspect of quality of care. In this study a positive effect of the implementation of the Resident Assessment Instrument in nursing home wards on this co-ordination of care was found. In this non-randomized controlled trial, the most positive improvement was found on the subscale case history. Improvements in the RAI group were also found for care plan and all the other aspects of co-ordination of care, when compared to non-RAI wards, but these improvements were smaller and not statistically significant.

The effects were partly due to a decrease in the quality of co-ordination of care in the comparison wards. Important items (total co-ordination of care, care plan and case history) however also show improvement without comparing with the non-RAI group.

Our findings confirm the positive effects on quality of care, especially the quality of documentation, which were reported in the USA, Sweden and Japan (Hawes et al, 1997; Ikegami et al 1997; Hansebo 1999). This study shows that the effects can be identified with an instrument that is not derived from the RAI/MDS itself, that they are internationally consistent, and that they hold when compared to a non-RAI group. However, in this study we employed a non-randomized control design and comparison wards did not have an alternative intervention.

The selection of comparison wards was based on comparable facility characteristics. Nevertheless, there was a significant difference in co-ordination of care base-line scores between the intervention and comparison wards. This seems to indicate that inter- and intra facility differences in quality of co-ordination of care are customary and that co-ordination of care is an aspect of quality of care, which is difficult to predict from structural characteristics of the facility.

The outcome, quality of co-ordination of care, was measured with an instrument which has been developed for Dutch nursing homes, but has not went through a meticulous validation to other instruments or measures. It is sensitive to poor quality and to change, but has not enough items to give a comprehensive picture or a threshold of the quality of co-ordination of care. It may therefore have been too restricted to sense other changes as a result of the RAI-implementation

The positive effect of RAI implementation on the quality of the case history was expected. The quality of the care plan also improved in the RAI group, but this was not statistically significant. The lack of definitive effects on care plan, communication and patient report is puzzling, as the RAI gives many tools to improve these aspects. One of the statistical explanations is the relative small number of wards examined, and the major differences (heterogeneity) in base-line quality scores and mean difference scores, which forced us to use a random effect model, instead of a fixed effect model. In a fixed effect model, confidence intervals are usually smaller. We believe that another explaining factor is that the time frame used in this study was short (8 months follow-up). In this period, 2 or 3 MDS-assessments for each resident should have been made, within an untroubled implementation scheme. But the RAI implementation in Dutch nursing homes has until so far not been without it's problems, and did in the wards we studied frequently not proceed according to the implementation plan. Simply filling out an MDS-form cannot improve quality of care. Further assessment of the identified problems (or risk of developing that problem) by using the RAPs is an essential part of the RAI. This study has also shown that our participating RAI nursing homes wards find this a difficult task. Furthermore, feedback to the wards about the care they are giving, based on outcomes, health and well-being of the residents is essential for quality enhancement. Software and database procedures to supply this feedback were however not yet operational during the time of our study.

Difficulties in obtaining (good) staff (a problem facing the care industry as a whole) and operational RAI-software have caused delayed and adjusted implementation, also in the nursing homes that were included in the study. Delivering better care also depends on availability and

quality of staff and resources. At the moment it is difficult for most Dutch nursing homes to find and employ enough and qualitative good staff, and this shortage is expected to last for several years. This could explain the decrease of quality of co-ordination of care (for all aspects but the care plan) in the comparison wards. Implementation of the RAI, be it not untroubled, may somehow protect a nursing home from implications of the staffing problems on the quality of care.

We conclude that the Resident Assessment instrument is capable of improving the quality of care in Nursing homes. Will individual residents benefit from this improvement? We found the RAI has led to better case history and better care plans, which could mean the resident needs are better assessed. Having a better care plan does however not necessarily mean the resident is better off (e.g. aspects of quality of life, well-being and health outcomes). (Schnelle 1997) Making use of the positive effects of the RAI on process quality to improve these aspects will be the next challenge for the nursing homes that have implemented the RAI. Attention should be paid to the use of the RAPs and to using feedback mechanisms for quality indicators and case-mix, to strive for a better quality care.

PART III:
INSIGHT IN FUNCTIONING USING MDS-DATA

Chapter 6
The effect of depression on social engagement*

* published as: Achterberg W, Pot AM, Kerkstra A, Ooms M, Muller M, Ribbe M. The effect of depression on social engagement in newly admitted Dutch nursing home residents.Gerontologist 2003;43(2):213-8.

Abstract

Purpose of the study:
To study the effect of depression (high levels of depressive symptoms) on social engagement
Design and Methods:
In 65 nursing homes in the Netherlands, 562 newly admitted residents were assessed at admission. Social engagement was measured with the MDS Index of Social Engagement. A multivariate logistic regression model was used to study the effect of depression, measured according to the MDS-depression rating scale and controlled for confounders, on social engagement.
Results: 51% of the newly admitted residents had a low level of social engagement; 27% were depressed (high levels of depressive symptoms). Residents with a depression were significantly more often found to have low social engagement (OR 3.3), and confounders did not influence the strength of this relationship. Low social engagement on admission is predicted by depression and low cognitive performance, and to a lesser extent by impairments in vision and ADL.
Implications: Low social engagement is very common in newly admitted nursing home residents, and depression is an important independent risk factor.

Introduction

Admission to a nursing home involves adapting to other people and other activities, creating new social relationships and finding resources for support while handicapped by all kinds of impairments. Well-being and satisfactory social functioning is not easy to establish in this context. Being successful in social engagement can be regarded as a critical component of quality of life for nursing home residents (Mor et al., 1995). It means that the resident has a high sense of initiative and involvement, and can respond adequately to social stimuli in the social environment: participate in social activities and interact with other residents and staff. Previous research has associated low social engagement with increased mortality (Kiely et al. 2000, Bennett 2002) and cognitive decline (Bassuk et al. 1999).

In the USA, positive aspects of social functioning were included in the Resident Assessment Instrument (RAI) that was mandated by Congress (Morris et al. 1990). In constructing the Minimum Data Set (MDS) for the RAI, considerable attention has been paid to well-being and social functioning. The MDS-items concerning social functioning focus on the engagement of residents in the social environment around them, and aim to measure their sense of initiative and involvement. The Index of Social Engagement, which is constructed from the 6 MDS-items on social engagement, reflects both social involvement and autonomy (Mor et al. 1995). The effect of several resident characteristics on social engagement have been studied; cognitive and ADL impairment were found to be related to low social engagement (Mor et al. 1995, Schroll et al. 1997, Frijters et al. 2001), as were sensory and communication losses (Resnick et al. 1997). The effect of depression on social engagement is unknown. Several studies have found that (minor or major) depression has a much higher prevalence in older inpatient populations than in the community (Rovner et al. 1991, Abrams et al. 1992, Falck et al. 1999, Parmelee et al. 1992). Furthermore, it is frequently not recognized and/or treated. Depressed residents are likely to have more difficulty in engaging themselves in the new environment, as residents who are not socially engaged are more likely to be depressed. Successful treatment of depression in addition to or instead of offering social activities may be the key to successful social engagement.

Previous research has been based on cross-sectional data, with a mixture of residents who had been in the nursing home for a variable period of time (Mor et al. 1995, Schroll et al. 1997, Resnick et al. 1997, Frijters et al. 2001). There is little known about the predictors, course and prevention of low social engagement. It is important to study the concept of low social engagement in newly admitted residents, because this can facilitate the development of preventive strategies.

The aim of this study is to explore the effects of depression on social engagement in newly admitted Dutch nursing home residents.

Design and methods

Design and sample:

In the Netherlands, there are 325 nursing homes with 53,800 beds (26 per 1000 elderly people) (Ribbe et al. 1997). Residents with dementia are admitted on specialized psychogeriatric units and residents with other diseases are often also differentiated in long term care, palliative or rehabilitation units. All nursing homes have specialized nursing home physicians in their staff (approximately 1 for every 100 residents).

The subjects in this study are participants in an observational study among newly admitted nursing home residents. The data-collection was carried out by registered physicians in a specialist training program for nursing home physicians. This vocational training consists of two years of medical practice in a teaching nursing home with a one-day theoretical course per week at a University Institute for Nursing Home Medicine (Hoek et al. 2001). This study was part of the research training, which is one of the elements of the core curriculum. In 65 nursing homes throughout the country, the physicians were asked to include and assess newly admitted residents. Residents who were re-admitted after a temporary discharge (less than 90 days) were excluded.

In total, 562 residents were assessed, 64.6 % of whom were female. The mean age was 78.5 (for females: 79.8, for males: 76.2), which is a representative sample compared to the national average. A relative large number of residents were admitted to psychogeriatric wards: 247 (44%), compared to the national average of 33.6% (SIG Zorginformatie 1998, Arcares, 1999) (see table 1). 254 residents (45.2%) were admitted for long term care. 226 (40.2%) were admitted for rehabilitation (117 of them [20.8%] in a ward for specialized rehabilitation care), 81 (14.4%) were admitted for other reasons (such as terminal care, screening/observation or crisis intervention), and 1 (0.2%) was not registered. As there are no national data available on the aims and type of ward described, it is not possible to make comparisons with our data. Because of missing values in independent variables, 543 residents were included in the multivariate logistic model.

Measurement instruments

All the variables were derived from the Resident Assessment Instrument (RAI) Minimum Data Set (MDS) 2.0 items on nursing home care (Morris et al. 1990). These items have shown good reliability in several countries (Morris et al. 1997, Sgadari et al. 1997). Because the Dutch nursing home physicians in training were instructed in the RAI-MDS and they are on the ward on a daily basis, they were expected to fill out the MDS themselves. Consultation of others however could take place.

Table 1: Comparison of characteristics of sample with characteristics of SIG Verpleeghuis Informatiesysteem (SIVIS) 1997/1998

	Study sample (n=562)	**Dutch average 1997/1998 (SIVIS/Arcares)[a]**	**Significance of the difference (p)**
% female	64.6	66.2	.43
Mean age male	76.2	76.6	.61
Mean age female	79.8	80.2	.45
% residents on psychogeriatric wards	44.0	32.5 (1998: 33.6)	< .0001 < .0001

[a]SIVIS has information on 35402 new admissions in 1997 (represents 81% of all Dutch NH's in 1997) (SIG Zorginformatie 1998).
For 1998 information on % female and mean age male/female is not described) (Arcares 1999).

Dependent variable

Social engagement was measured with the Index of Social Engagement (ISE), which is constructed with the 6 following (dichotomous) MDS-items: 1- at ease interacting with others, 2- at ease doing planned or structured activities, 3- at ease doing self-initiated activities, 4- establishes own goals, 5- pursues involvement in life of facility and 6- accepts invitations into most group activities. The ISE ranges from 0 (=lowest) to 6 (=highest level of social engagement). The items have shown moderately good inter-rater reliability (Sgadari et al., 1997). In the present sample the six items demonstrated reasonable internal consistency (Cronbach's alpha = .72).

The ISE measures a single construct that is correlated with actual participation in the activities in the nursing home, and is distinct from measures for mood, behavioral problems and conflicts in relationships (Mor et al. 1995).

The ISE has been dichotomized in two different ways: 0-2 versus 3-6 (sensitive for low social engagement) (Resnick et al. 1997) and 0-4 versus 5-6 (sensitive for high social engagement) (Schroll et al. 1997). Because this study is looking for factors associated with low social engagement, the 0-2 (low) versus 3-6 (not low) is used.

Independent variable

Mood/depression:

The MDS Depression Rating Scale (DRS) is a 7-item scale, with all items to be scored 0 (indicator not exhibited), 1 (indicator of this type exhibited at least once in the last 30 days and up to 5 days a week) or 2 (indicator exhibited daily or almost daily) (Burrows et al. 2000). The scores range between 0 and 14. The mood-items in the MDS 2.0 have good inter-rater reliability

(Morris et al. 1997). In the present sample the seven items demonstrated good internal consistency (Cronbach's alpha = .87).
With a cut-point of 3, it differentiates well between residents with few or many depressive symptoms. Compared to (DSM-IV) psychiatric criteria for depression it has a high sensitivity (91%), and a lower specificity (69%) (Burrows et al. 2000). This scale has been used therefore in this study in order to distinguish between residents with or without (easily observed) depressive symptoms. Therefore, where the word 'depression' is used, it means a relatively high level of depressive symptoms.

Control variables
Cognitive function was measured according to the MDS-Cognitive Performance Scale (CPS), which is based on 5 MDS-items. The CPS is a seven-category index, ranging from cognitively intact to very severely impaired (Morris et al. 1994). It has shown substantial agreement with the Mini-Mental State Examination (MMSE) in the identification of cognitive impairment in research settings (Hartmaier et al., 1995). The index is dichotomized by combining the three severe categories as 'low' cognitive performance and the four other categories as 'high' cognitive performance (Mor et al. 1995).

The *ADL classification* is based on 6 MDS-items on self performance of ADL, each consisting of 5 categories, ranging from independent to totally dependent, and one item concerning urinary incontinence.
The seven-category (hierarchical) ADL-index ranges from minor oversight to highly dependent. The ADL-index is dichotomized, with the four highest scores classified as dependent, and the three lower scores as relatively independent (Mor et al. 1995).

Hearing and *vision* were measured according to two 4-level ordinal MDS-items, which assess the ability to see or hear with environmental adjustments (such as glasses or hearing aids). 'Adequate' and 'minimal impairment' is dichotomized as no problems, and 'moderate impairment' and 'severe impairment' as problems with hearing or seeing.

The demographic variables are sex, ward type (somatic, psychogeriatric or rehabilitation) and age (in 4 categories: <65, 65-74, 75-84, >=85).

Analysis

First, univariate logistic regression analysis was applied (SPSS 10.1) to identify variables related to low social engagement. Subsequently, correlations between dependent and independent variables were studied using Chi-Square statistics. For the effect of depression on social engagement possible confounders were entered one by one in a multivariate logistic regression model, to determine the true effect of depression. In the final equation the 95% confidence intervals were calculated.

Results

The mean Index of Social Engagement for all residents was 2.62 (SD 1.84) and 51.4% had low social engagement (= 0, 1 and 2). The item with the most positive answers was "at ease interacting with others" (71.2%); the item with the least positive answers (30.6%) was "pursues involvement in life of facility". The prevalence of depression in the sample, according to the DRS (>2), was 27%; 19% had low cognition (=CPS 4-6), 56.7% had ADL-loss (=ADL 3-6), 34.7% had problems with vision and 27.0% had problems with hearing.

Cognition had a strong relation with low social engagement (p <.001) and a weaker relation with depression (p =. 045) (see table 2). Problems with cognition, hearing and seeing, and ward type were all associated with depression and low social engagement, and could therefore be potential confounders (correlation with both dependent and independent variable) in the relation between depression and social engagement. (see table 2)

There were no significant correlations for ADL/depression or sex and age and depression/social engagement. Despite this, ADL and sex and age were included as possible confounders in the model, because of the plausibility that these impairments could alter the strength of the effect of depression on social engagement.

In univariate regression, cognition (OR 4.2), vision (OR 2.2), hearing (OR 1.5) and ADL (OR 1.9) were significantly related to low social engagement; the demographic variables of sex and age were not. Depression is highly associated with low social engagement (OR= 3.5, 95% CI: 2.3, 5.3), and controlling in the multivariate logistic model for possible confounders made little difference to the strength of this (OR=3.3, 95% CI: 2.1, 5.1). (See Table 3) In this model, low cognitive performance is predictive (OR 3.5, p< .001), as is vision (OR: 1.7, p= .011). (Table 3) The presented multivariate logistic model creates a predictive model with 66.4% overall correctly predicted (.5 cut-off value).

Table 2: Distribution of dependent and independent variables (Chi-Square Fischer's exact 2-sided for dichotomous variables and Pearson Chi-Square 2-sided for categorical variables) for 543 residents who were included in the multivariate regression analysis

N=543	**Depression**			**social engagement**		
	Yes (n=145)	**No (n=398)**	**p**	**Low (n=271)**	**High (n=272)**	p
Low social engagement	72.4%	41.7%	<.001	-	-	
Depression	-	-		38.7%	14.7%	<.001
Cognition low	24.1%	16.3%	.045	28%	8.8%	<.001
Seeing problems	45.5%	30.7%	.002	43.2%	26.1%	<.001
Hearing problems	33.8%	24.4%	.037	30.6%	23.2%	.053
ADL impairment	35.9%	34.9%	.840	38.7%	31.6%	.088
Male	35.2%	34.7%		37.3%	32.4%	.242
Age <65	3.4%	8.8%		5.5%	9.2%	
65-74	15.9%	16.8%		16.6%	16.5%	
75-84	49%	46.5%	.182	46.5%	47.8%	.300
>=85	31.7%	27.9%		31.4%	26.5%	
Ward Somatic	31%	32.2%		33.2%	30.5%	
Psychogeriatric	55.9%	40.2%	<.001	49.1%	39.7%	.003
Rehabilitation	13.1%	27.6%		17.7%	29.8%	

Table 3: Multivariate logistic model for determinants of low social engagement in newly admitted (n=543) Dutch nursing home residents

	OR	95% CI	p (Wald)
Depression	3.3	2.1, 5.1	<.001
Cognition	3.5	2.0, 6.1	<.001
Vision	1.7	1.1, 2.5	.011
Hearing	1.0	0.7, 1.6	NS (.846)
ADL	1.4	1.1, 2.1	NS (.083)
Sex	0.8	0.5, 1,2	NS (.230)
Ward somatic (indicator)			NS (.665)
Ward psychogeriatric	0.9	0.5, 1.4	NS (.861)
Ward rehabilitation	0.8	0.5, 1.3	NS (.797)
Age < 65 (indicator)			NS (.710)
Age 65-74	1.6	0.7, 3.7	NS (.261)
Age 75-84	1.5	0.7, 3.2	NS (.322)
Age >=85	1.6	0.7, 3.6	NS (.286)

Discussion

More than half of all newly admitted Dutch nursing home residents have low social engagement. This is a high prevalence, because social engagement is a measure for quality of life, and low social engagement is associated with cognitive decline and mortality (Mor et al. 1995, Bassuk et al. 1999, Kiely et al. 2000, Bennett 2002). In this study, residents were assessed within 10 days after admission. It is possible that it takes residents longer to achieve optimal social engagement. However, in the available cross-sectional data on social engagement even worse scores are reported: 68% low social engagement in the USA (Resnick et al. 1997), and apparently even worse in European countries and Japan (Schroll et al. 1997). It is still unclear whether social engagement declines or increases in the weeks and months after admission. This question will be addressed in a future study using longitudinal data.

The effect of depression on social engagement was found to be strong, and there were no confounding mechanisms. With our cross-sectional sample, we can not establish a causal relationship, but it is theoretically plausible that depressive symptoms (such as anxiety, withdrawal and loss of interest) can act as obstacles in the receptiveness of a resident in responding to social stimuli. The relationship of depression and cognitive decline with social

engagement was found to be stronger than the relationship between sensory or ADL-impairment and social engagement. The strong univariate correlation between ward types and social engagement did not hold in the multivariate model, which means the differences between the wards are explained by different levels of depression and functional (mainly cognitive) impairments.

One limitation of this study might be that the participating residents were recruited in teaching nursing homes. Some physicians/homes included more patients than others and there was an over-representation of psychogeriatric residents. The model controlled for cognitive status, so this is not likely to affect the validity of the results. Moreover, age and sex-distributions were representative of all newly admitted nursing home residents in the Netherlands (SIG Zorginformatie 1998, Arcares 1999). It is not known whether our sample was representative for the percentage of residents on specialized rehabilitation wards, but in our multivariate logistic model we controlled for ward type. Another limitation is that this was a cross-sectional sample of newly admitted residents. The depression scores might therefore be higher and the social engagement scores lower because of the impact of institutionalization, and may subsequently change over time. Longitudinal data are needed to study the longitudinal relationship between depression and social engagement.

One of the strengths of this study is that the data-collection was solely intended for research purposes, and performed by trained physicians. In such a setting, there is little reason to dispute the reliability of the MDS-data (Teresi & Holmes 1992, Hawes et al. 1992, Ouslander 1994). Moreover, the sample was relatively large (1.3% of all Dutch nursing home admissions), and collected from a wide variety of nursing homes throughout the country (18% of all Dutch nursing homes). There are no data on the reliability of the MDS when physicians fill it out. Dutch nursing home physicians are responsible for the multi-disciplinary care planning of all residents, and are therefore very well informed about their functional and social abilities. We can not rule out the possibility that the social engagement items would be interpreted on a different way when they are conducted solely by a nurse, but we have no reason to believe this has created any bias.

Nursing homes should provide care and a customized living environment for frail residents. This should include, in addition to adequate treatment and personal care, facilitating psychosocial well-being and social interaction. Thorough assessment, immediately on admission, of these psychosocial needs is imperative. Depression should be recognized and treated. The MDS-depression algorithm (which contains 5 more items next to the 12 items of the DRS, and is triggered when at least one of them is positive) seems to provide too little specific information: in our sample 68% of the residents had at least one DRS item scored positive. Such a sensitive trigger in the busy nursing home practice is in time likely to be ignored. Recognition and adequate staff reaction could be improved by using a more specific measure, like the DRS cut-point of 3.

The results of this study also suggest that more attention should be paid to activities that are appropriate for residents with cognitive decline and (many) depressive symptoms. This will be a challenge, as depressed residents are not very inclined to respond to invitations to take part in (group) activities. For the well-being of residents with low social engagement and many depressive symptoms (in this sample 19.6% of all newly admitted!), it is essential that this challenge is taken on.

Chapter 7
The impact of previous place of residence on depressive symptoms*

* submitted for publication as: Achterberg WP, Pot AM, Kerkstra A, Ribbe MW. A cross-sectional study on risk indicators of depressive symptoms in recently admitted Dutch nursing home residents: the impact of previous place of residence

Abstract

Objectives: To study risk-indicators for depressive symptoms in a sample of recently admitted nursing home residents. The hypothesis was that nursing home admission after living independently (*own home*) is a stronger risk indicator for depressive symptoms than admission after staying in a more institutional (*hospital and residential facility*) environment.

Design: Multi-center, cross-sectional, observational study of newly admitted nursing home residents.

Setting: 65 nursing homes in the Netherlands

Participants: 562 residents (mean age 78.5, range 28-101, 64.6% female)

Measurements: Minimum Data Set (MDS) Depression Rating Scale. Previous place of residence was studied as a risk indicator controlled for demographic, social and health related (vulnerability) factors measured with the MDS. Trained physicians performed the assessments.

Results: Being admitted from one's own home (compared with admission from an institutional setting) was an independent risk-indicator for depressive symptoms (OR 2.0, *P*= .002) controlled for social and health related variables. The most important control variables (associated to depressive symptoms) were: the use of anxiolytic medication (OR 3.8, *P*< .001), low social engagement (OR 2.7, *P*< .001), and mild (OR 2.2, p= .038) or moderate (OR 2.3, *P*= .008) cognitive impairment.

Conclusion: Residents who are admitted into a nursing home from their own home have more depressive symptoms than residents who are admitted from institutions. These results might be beneficial in the recognition, prevention and management of depressive symptoms in nursing homes.

Introduction

Depressive symptoms and depressive disorders are highly prevalent in nursing homes, much more than in community-dwelling elderly (Jongenelis et al. 2003). The impact of serious mood disorders on quality of life, mortality and costs of health care is considerable (Beekman et al. 2002). Depression is a multifactorial disorder, and though there are numerous different models to explain the origin of depression, there basis is usually a stress-vulnerability model (Beekman 1996). In this model, provoking agents (stressors like life events and ongoing conflicts) can bring on depressive symptoms, modified by vulnerability and resilience factors.

In the *vulnerability-stress model* for late life depression, destabilization (getting symptoms) is the result of long-lasting vulnerability acting in concert with exposure to environmental stressors, usually one or more highly stressful events (Beekman 1996, Brown 1978, Goldberg et al. 1992). Admission to a nursing home may be such a provoking life event. Residents often feel displaced, vulnerable and abandoned in the first weeks after admission (Patterson 1995). The reason for nursing home admission is mostly related to chronic disease and impaired physical or cognitive functioning, so this stressor acts in a vulnerable background, enhancing the risk of developing depression.

There has been little research on the impact of nursing home admission on the development of depressive symptoms (Lee et al. 2002). Admission is related to losses in several respects: a loss of autonomy and confidence but also a loss of possessions and one's own familiar environment. It may be more stressful to be placed in a nursing home for those admitted from home than for those who come from another institutional setting, like a residential facility or hospital.

The previous place of residence was analyzed in this study as a predictor for depressive symptoms in newly admitted nursing home residents.

Methods

Design and sample:

There are 325 nursing homes with 53,800 beds in the Netherlands, (26 beds per 1000 elderly people) (Ribbe et al. 1997). Residents with dementia are admitted to specialized psychogeriatric units and residents with other main diagnoses are cared for in long term, so called 'somatic' wards, or rehabilitation units. All nursing homes have specialized nursing home physicians in their staff (approximately 1 for every 100 residents) (Hoek et al. 2003).

This study uses data of an observational study among newly admitted nursing home residents. Registered physicians in a research module of the specialist training program for nursing home physicians collected the data (Hoek et al. 2001). The physicians included and assessed newly admitted residents in 65 nursing homes throughout the country, within 10 days after admission. These homes all were connected to the specialist training program for nursing home physicians at the Vrije Universiteit University Medical Centre. Being re-admitted after a temporary discharge (less than 90 days) was the only exclusion criterium. The physicians were stimulated to include all admitted residents, but if this intervened with other curriculum activities, other *random* inclusion methods were allowed (e.g. the first 5 new admissions, or the first of every 5

new admissions). All assessments were performed between 13 January 1998 and 24 February 1999.
562 residents were assessed, 64.6 % of whom was female. The mean age was 78.5 (for females: 79.8, for males: 76.2), which is a representative sample of all new admissions (Achterberg et al. 2003, Arcares 1999).
This sample had significant more residents admitted on psychogeriatric wards than the 1998 national average (44% versus 33.6%), and less residents admitted from the hospital (27.2% versus 49.7%) (Arcares 1999).
The study was approved by the ethical committee of the Vrije Universiteit Medical Centre.

Measurement instruments
Parts of the Resident Assessment Instrument (RAI) Minimum Data Set (MDS) 2.0 were used to collect a broad range of information on residents' functioning (Morris et al. 1990). MDS items have shown good reliability in several studies and countries (Morris et al. 1997, Sgadari et al. 1997).

Dependent variable
Mood/depressive symptoms:
The MDS Depression Rating Scale (DRS) is a 7-item scale, with all items to be scored 0 (indicator not exhibited), 1 (indicator of this type exhibited at least once in the last 30 days and up to 5 days a week) or 2 (indicator exhibited daily or almost daily) (Burrows et al. 2000). The scores range between 0 and 14. The mood-items in the MDS 2.0 have good inter-rater reliability (Morris et al. 1997). In the present sample the seven items demonstrated good internal consistency (Cronbach alpha = 0.87).

Using a cut-off of 3 and compared with (DSM-IV) psychiatric criteria for depression, it has a high sensitivity (91%) and a lower specificity (69%) (Burrows et al. 2000). This scale is used in this study in order to distinguish between residents with relatively many or few (easily observed) depressive symptoms. This cutoff however does not imply that a serious depressive disorder is always present.

Change in depression
We have no data on the mood status before admission, but we did incorporate the MDS item: change in depression in the last 30 days (no change/ improvement/deterioration).

Independent variables
Previous place of residence (the stressor) was dichotomized into '*admitted from home*' and '*not admitted from home*': hospital, home for the aged, other nursing home, other residential living facility, psychiatric hospital, rehabilitation center and other. (See table 1)

Demographic variables:

Gender, age (in four categories: <65, 65-74, 75-84, >=85), *education* (in three categories: low, medium, high) and *primary language* (Dutch versus other).

Social functioning:

Social engagement was measured with the MDS Index of Social Engagement (ISE). The ISE measures a single construct that is correlated with actual participation in the activities in the nursing home, and is distinct from measures for mood, behavioral problems and conflicts in relationships.(17) The ISE was dichotomized 0-2 versus 3-6 (Achterberg et al. 2003, Resnick et al 1997). In addition, the *marital status* before admission was registered as living alone or living with partner

Health related variables:

Pain was measured using the MDS-item J2a (pain frequency). It was dichotomized into never pain versus daily or less than daily pain.

The relation between specific disease diagnoses and depressive symptoms is not clear. Many diagnoses were recorded. Diagnoses that have been found or suggested to have an association with depressive symptoms in previous studies were selected for the analysis (Jongenelis et al. 2003, Beekman 1996, Penninx et al. 1996, Turvey et al. 2002). The following were used in the analysis: Any malignancy, Chronic Obstructive Pulmonary Disease (COPD), diabetes, osteoarthritis or rheumatoid arthritis and heart failure, and the potential etiological diagnoses dementia, Parkinson's disease and stroke. The use of anxiolytic, antipsychotic and hypnotic medication was dichotomized as none versus at least one prescription in the last week. This approach of treating patients who receive 1-6 days of medication the same as patients who receive 7 days of medication during the last week, is (among others) based on the antipsychotic drug Penfluridol, which is relatively frequent used in the Netherlands. It is dosed once a week, the drug remains therapeutic for 7 days. 130 patients used antipsychotics 7 days during the last week, 16 patients used antipsychotics 1 day a week, and only 9 patients were coded as 2, 3, 4, 5 or 6 days the last week. These patients could also have had chronic medication, which had been stopped somewhere in the last week. Effects and side-effects of antipsychotics are known not to disappear immediately after cessation of the medication. Therefore, no difference was made for patients who received medication daily or less than daily in the analysis.

The *ADL classification* based on a seven-category (hierarchical) ADL-index ranges from minor oversight to highly dependent. The ADL-index is dichotomized, with the four highest scores classified as dependent, and the three lower scores as relatively independent (Mor et al. 1995).

The MDS sensory items are: *hearing* (4-point scale) and *vision* (5-point scale). They measure the ability to see or hear with environmental adjustments (such as glasses or hearing aids). Scores were dichotomized as no problems ('Adequate' or 'minimal impairment') versus problems with hearing or seeing: moderate or severe (or with vision: very severe) impairment.

Cognitive function was measured with the MDS-Cognitive Performance Scale (CPS), which is based on 5 MDS-items. The CPS is a seven-category index, ranging from cognitively intact to very severely impaired (Morris et al. 1994). It has shown substantial agreement with the Mini-Mental State Examination (MMSE) in the identification of cognitive impairment in research settings (Hartmaier et al. 1995). The index is dichotomized by combining the three severe categories as 'low' cognitive performance and the four other categories as 'high' cognitive performance (Mor et al. 1995).

Analysis

Multivariate logistic regression was performed in three sets of conceptually related factors: demographics, health related variables and social functioning. This approach limits the number of risk indicators, and decreases the risk of collinearity among those risk indicators (Beurs de et al. 2001). In variables with more than two categories, the first group (usually the one with the least a priori chance of depression) was the reference group. Also an analysis was performed using the scale-scores for pain, ADL and cognition to minimize loss of information because of the dichotomization.

Factors which were related to depressive symptoms in one of these groups of related variables ($p<.20$) were used in the final multivariate logistic regression model (SPSS 10.1).

Models were created in post hoc analysis which controlled for the use of antidepressive medication, as a measure for the quality of mental care before admission.

Table 1: Previous Place of Residence for 562 Newly Admitted Dutch Nursing Home Residents Compared with the National Dutch Average of 1998

	n (%)	**Dutch average 1998***
Home	221 (39.3)	34.8%
Hospital	153 (27.2)	49.7%
Home for the aged	58 (10.3)	11.8%
Other nursing home	66 (11.7)	3.3%
Other Residential living arrangements	30 (5.3)	
Psychiatric hospital	10 (1.8)	
Rehabilitation centre	1 (0.2)	
Other	23 (4.1)	0.4

[a]There were 42658 new nursing home admissions in the Netherlands in 1998. Average 1998 data represent 75% of all Dutch nursing homes in 1998 (Arcares 1998).

Results

The prevalence of depressive symptoms (DRS ≥ 3) for all 562 residents was 26.9%. 221 (39.3%) residents were admitted from their own home (table 1). These residents had (bivariate) significant higher prevalence of depressive symptoms (OR 1.85, 95% CI: 1.27-2.70; p= .001).

Demographics

Multivariate logistic regression analysis of the demographic variables revealed no significant correlations with depressive symptoms for language, gender or education. For age, there was a trend that the oldest (>85) had more depressive symptoms than the youngest group (<65; p=.076, table 2).

Table 2: Distribution of Demographic Variables and results of Multivariate Logistic Regression (MDS Depression Rating Scale >2 Dependent Variable)

	Descriptive statistics		**Multivariate logistic regression**	
	n*	**%**	***p***	**Adj OR (95% CI)**
Female	363	64.6	.884	1.03 (0.67-1.59)
Age (n=560)				
<65 (reference)	42	7.5	.336	-
65-74	96	17.1	.237	1.82 (0.68-4.91)
75-84	261	46.6	.115	2.10 (0.84-5.29)
>=85	161	28.8	.076	2.37 (0.91-6.14)
Language not Dutch	36	6.4	.357	0.65 (0.26-1.63)
Education (n=556)				
-low (reference)	280	50.4	.741	-
-medium	235	42.3	.737	0.93 (0.62-1.40)
- high	41	7.4	.559	1.24 (0.60-2.57)

* n=562 for descriptives unless otherwise stated, n=554 for the multivariate model due to missing values; MDS: Minimum Data Set. Adj OR: Adjusted Odds Ratio

Health and functioning

Cognitive performance (OR 1.58, 95% CI=1.08-2.85) and the use of anxiolytics (OR 3.65, 95% CI=1.9-7.03) and antipsychotics (OR 1.77 95% CI=1.10-2.86) were associated with depressive symptoms. The associations reached the significant (p < .20) selection criterion for the final multivariate model for the following diagnoses: heart failure, COPD and hearing and visual impairments (table 3). Other health measures did not reach this significance level. In the model in which ADL and pain were not dichotomized, but studied as categorical variables, results were still not significant. A model in which all diagnoses were exchanged for the number of diagnoses did not reveal a significant association for number of diagnoses with depressive symptoms.

Table 3: Distribution of Health Related Variables and Multivariate Logistic Regression (MDS Depression Rating Scale >2 Dependent Variable)

	Descriptive statistics		Multivariate logistic regression		
	n*	**%**	***p***	**Adj OR**	**95% CI**
Pain (daily or less than daily) (n=560)	282	50.4	.467	1.18	0.76-1.82
Malignancy (any)	32	5.7	.756	0.86	0.33-2.22
COPD	69	12.3	.133	1.58	0.87-2.85
Diabetes	95	16.9	.900	0.97	0.56-1.67
Heart failure	87	15.5	.123	0.63	0.35-1.14
Arthrosis rheumatoid arthritis	99	17.6	.654	1.13	0.67-1.91
Dementia	132	23.5	.929	1.02	0.61-1.72
Stroke	122	21.7	.743	1.09	0.65-1.82
Parkinson's	23	4.1	.932	1.05	0.38-2.85
ADL (561) early loss	243	43.3	.662	1.10	0.72-1.67
Hearing impairments (560)	151	27.0	.102	1.46	0.93-2.31
Visual impairments (556)	193	34.7	.071	1.49	0.97-2.31
Cognition low (556) 0-2	302	54.3	.022	1.58	1.08-2.85
Use of anxiolytics	46	8.2	< .001	3.65	1.90-7.03
Use of antipsychotics	155	27.6	.019	1.77	1.10-2.86
Use of hypnotics	190	33.8	.276	1.26	0.83-1.93

* n=562 for descriptives unless otherwise stated, n=548 for the multivariate model due to missing values. 95% CI: 95% Confidence Interval. MDS: Minimum Data Set. COPD: Chronic Obstructive Pulmonary Disease. ADL: Activities of Daily Living. Adj OR: Adjusted Odds Ratio

Social functioning

Low social engagement was significantly associated with depressive symptoms (OR 3.3, 95% CI= 2.25-5.22), *having a partner* was not associated with depressive symptoms) (table 4).

Final multivariate model

Residents who were admitted from their own home had higher prevalence of depressive symptoms in the final multivariate model (table 5) (OR 1.97,95% CI=1.30-3.01; p= .002). The use of anxiolytics had a significant and strong relation with depressive symptoms (OR 3.8) in this multivariate regression model. In addition, also low social engagement was associated with depressive symptoms (OR 2.7). The relationship of depressive symptoms and cognition is somewhat more complicated: only for mild or moderate impairment (CPS 2 and 3) there was a significant relationship. The use of antipsychotics, heart failure, COPD, visual impairment and hearing impairment were not independently associated with depressive symptoms.

A possible other confounder of the relation between residency before admission and depressive symptoms could be the type of ward on which they were admitted. Residents coming from home were much more likely to be admitted on a psychogeriatric ward (54.4% versus 37.9%), and much less on a rehabilitation ward (17.1% versus 27.1%) or somatic ward (28.6% versus 35%, Chi-square p< .001). The prevalence of depressive symptoms differed between those wards: the prevalence was 14.7% on rehabilitation wards, 26.7% on the somatic wards and 32.8% on the psychogeriatric wards. In multivariate regression analysis with previous place of residence and ward type, previous place of residence remained an independent risk indicator (OR 1.7; 95% CI 1.2-2.5; p= 0.008), also rehabilitation ward remained an independent (positive) risk indicator in contrast to the psychogeriatric ward (OR 0.49; 95% CI 0.27-0.88; p=0.017). Ward type was no effect-modifier (the interaction of the variables previous place of residence/ward type was not statistically significant). The relation between the previous place of residence and depressive symptoms might be caused by differences in quality of (mental) care before admission, for example the use of antidepressive medication at admission: 7.7% of residents admitted from their own home used antidepressive medication versus 12.9% of residents admitted from other settings. In a multivariate model with previous place of residence but controlled for antidepressive medication use, the relation of previous place of residence with depressive symptoms did not change (OR: 1.9; 95% CI: 1.3-2.8). Antidepressive medication was also no effect-modifier.

Table 4: Distribution of Social Functioning Variables and Multivariate Logistic Regression (MDS Depression Rating Scale >2 Dependent Variable)

	Descriptive statistics		**Multivariate logistic regression**		
	n*	**%**	***p***	**Adj OR**	**95% CI**
Living with partner (n=560)	231	42.3	.940	1.02	0.69-1.50
Low Social engagement	289	51.4	<.001	3.43	2.25-5.22

* n=562 for descriptives unless otherwise stated, n=559 for the multivariate model due to missing values 95% CI: 95% Confidence Interval Adj OR: Adjusted Odds Ratio

In table 6, the distribution of the MDS item: *change in mood in the last 30 days* is shown. There were relatively less residents admitted form their own home who had no change in mood (more improved and more deteriorated) but Chi-square analysis showed no significance in these differences in changes.

Table 5: Multivariate Logistic Regression Model with Selected Health and Social Functioning (Vulnerability) Factors and the Stressor 'Admission from Own Home' (n=549)

	p	Adj OR	95% CI
Residence before admission: own home	**.002**	**1.97**	**1.30-3.01**
Control variables:			
Cognition			
Intact (CPS 0)-indicator (n=191)	.183	-	
Borderline intact (CPS 1) (n=54)	.263	1.56	0.72-3.38
mild impairment (CPS 2) (n=57)	**.038**	**2.21**	**1.05-4.67**
moderate impairment (CPS 3) (n=149)	**.008**	**2.31**	**1.25-4.27**
moderate severe impairment (CPS 4) (n=3)	.695	1.64	0.14-19.32
severely impaired (CPS 5) (n=83)	.219	1.58	0.76-3.25
very severe impaired (CPS 6) (n=19)	.810	1.16	0.34-3.94
Heart failure	.234	0.69	0.38-1.27
COPD	.144	1.56	0.86-2.83
use of anxiolytics	**<.001**	**3.79**	**1.92-7.50**
Use of antipsychotics	.092	1.51	0.94-2.43
Visual impairments	.165	1.38	0.88-2.16
Hearing impairments	.184	1.37	0.86-2.20
Low social engagement	**<.001**	**2.72**	**1.73-4.27**

COPD: Chronic Obstructive Pulmonary Disease. Adj OR: Adjusted Odds Ratio

Table 6: MDS item: change in depression the last 30 days

	Own home	other	
No change	144 (65.5%)	249 (73.2%)	393 (70.2%)
improvement	25(11.4%)	32 (9.4%)	57 (10.2%)
deterioration	51 (23.2%)	59 (17.4%)	110 (19.6%)
total	220	340	560

Discussion

This study shows that moving from one's own home to a nursing home is strongly associated In table 6, the distribution of the MDS item: *change in mood in the last 30 days* is shown. There were relatively less residents admitted form their own home who had no change in mood (more improved and more deteriorated) but Chi-square analysis showed no significance in these differences in changes.

with depressive symptoms, also after controlling for other important risk indicators. This may be explained by the loss of autonomy and one's own environment, and the difficulties to adjust to the life in an institution. The stress of admission may be enhanced by the dramatic sequence of events which often precedes admission, such as losing loved ones and emerging physical dependence (Spagnoli et al. 1986). The little research that has been done on this subject, suggests that the adjustment process takes 3 to 6 months, in four major phases: disorganization, reorganization, relationship building and stabilization (Patterson 1995). This adjustment process could be different for residents who come from their own home as compared with those who are admitted from other settings. This may be a relevant subject for future research in this field. Interestingly, we found small (and not significant) differences for residents admitted from their own home compared to residents from others settings for the MDS-item: *change in mood in the last 30 days*. This may suggest that this single retrospective MDS-item is not sensitive enough to measure these changes, or that the differences that we established already exist before admission, and therefore may actually be independent of the admission. This warrants further study.

There was no correlation of depressive symptoms with important health factors like dementia, stroke and Parkinson's disease, ADL-impairment and pain. A recent review showed that relationships between health related variables, except pain, and depression are usually found in nursing homes (Jongenelis et al. 2003). The explanation of the unexpected results of this study might be that this study controlled for a large variety of potential confounders, which is often not done in other studies. The participants were probably relatively unhealthy and impaired, much more than in previous research. One has to have complex and serious functional or health problems to be eligible for admission in a Dutch nursing home. This study did not exclude on health or functional criteria, as others have done (Jongenelis et al. 2003).

Associations between health and depression in newly admitted nursing home residents have been found using a self-rated health measure, which is however sensitive for report and recall bias (Godlove Mozzley et al. 2000). This study used observational data collected by trained physicians.

Several other risk-indicators for which we controlled showed a relationship with depressive symptoms in addition to previous place of residence. Mild or moderate (but not more severe) cognitive impairment was related with depressive symptoms. This is in concordance with biological theories of neuronal degeneration explaining the concurrent presence of depression and dementia (Zubenko & Moosy 1989). It is also in line with a more psychological approach of the effects of the awareness of cognitive deficits on mood (Sevush & Leve 1993). The inconclusive results on the relation between cognition and depression that were reported

previously are possibly based on this nonlinear correlation (Jongenelis et al. 2003). It may also reflect a lack of sensitivity of the MDS-DRS in detecting depressive symptoms in severely cognitive impaired residents.

Another control variable (the use of anxiolytics and to lesser extent antipsychotics) remained strongly associated with depressive symptoms in the final multivariate model. These medications can induce depressive symptoms, but they are also often inappropriately prescribed to treat depressive symptoms (Dhondt et al 2003, Evers et al. 2002).

Low social engagement is a strong and independent correlate of depression, in addition to previous place of residence. Social engagement is directly related to participation in the activities and life of the facility (Burrows et al. 2000). Depressed residents are not very inclined to take part in (group) activities, and social isolation may enhance mood disorders (Achterberg et al. 2003). This complex interaction deserves further, longitudinal study. Residents admitted on rehabilitation wards have less depressive symptoms, and this may in part be explained by the expected positive effect of the anticipation of discharge.

It is important to note that the MDS-DRS is not a diagnostic instrument, but measures observable depressive symptoms. In this study it was used as an indicator of relatively few or many symptoms. The prevalence rate of depressive symptoms (above cut-off of 3) found in this study is in line with others who used the MDS-DRS in cross-sectional samples in The Netherlands (prevalence 31%) and Canada (30%) (Holtkamp 2003). It is lower than the average prevalence rate found in nursing homes in 15 studies in which the Geriatric Depression Scale (GDS) was used as a screenings instrument: 44% (Jongenelis et al. 2003). Using a questionnaire (GDS) or observational instrument (MDS-DRS) may lead to other types of bias. Cognitively impaired and dysphatic residents are usually excluded in studies using the GDS, but they were included in this observational study. However, depressive symptoms are not always detectable by verbal, facial or non-verbal expressions, which may be one of the reasons for the poor recognition of mood disorders. In one, although small, sample, the MDS-DRS performed better (more sensitive and more specific) than the GDS (Sgadari et al. 1997). More recently, the MDS-DRS was found to have acceptable specificity but low sensitivity, compared with the GDS and Hamilton depression rating scale (Anderson et al. 2003). The internal consistency of the MDS-DRS was much lower in that study (Cronbach alfa: 0.67) than in this study (0.87), which raises questions about the reliability of these data. If data are not collected on a reliable manner (for instance if facilities only see the MDS as an administrative obligation) the validity must indeed be questioned. The American Geriatric Society and American Association for Geriatric Psychiatry (2003) recommended that besides the MDS, other depression screening instruments should be conducted routinely 2-4 weeks after admission and thereafter every 6 months. If routine data collection in daily practice might be unreliable because of the administrative burden, this is also likely to be the case for these other screening instruments.

This data collection was solely intended for research purposes, and performed by trained physicians. In this setting, there is little reason to dispute the reliability of the MDS, and the

MDS-DRS in recognizing residents with many or few depressive symptoms (Teresi & Holmes 1992, Hawes et al 1992, Ouslander 1994).

The sampling procedure excluded an unknown number of residents, but not on the basis of resident characteristics. Therefore, this is unlikely to have resulted in selection-bias. The studied sample was not completely representative of all Dutch nursing home admissions: more residents were admitted on psychogeriatric wards, and there were fewer residents admitted from the hospital. This is probably a reflection of the allocated wards for the physicians in training in this stage of their program (less rehabilitation and more psychogeriatric wards). The over-sampling of psychogeriatric residents and under-sampling of residents admitted from the hospital will have no impact on the internal validity, but might decrease the external validity. Future studies in other countries and samples are needed to establish the generalizibility of our results.

This was a cross-sectional sample of newly admitted residents. Longitudinal data are needed to better understand the relationship and interaction between stressors (like previous place of residents), vulnerability and depression.

This study did not find important health related risk-indicators for depression, but it might well be that health indicators influence the *course* of depressive symptoms. Future studies on the effects of nursing home admission should also measure depressive symptoms before admission, as it is known that depressive symptoms are associated with an increased risk of hospitalization and care utilization (Beekman et al. 2002, Huang et al. 2000). In the nursing home however, it is not known what the impact of depression is on care utilization. Future research should include utilization measures like hospitalization rate, the number of visits by the nursing home physician and increased non-psychotropic medication use.

Depressive disorders in the elderly and the nursing home often remain undiagnosed and untreated conditions, though there might have been an improvement in the last years (Chrystal et al. 2003). These results raises the question whether targeted detection, prevention and management programs for depression are more effective when they start prior to or directly after admission, especially for those who have no prior institutional history. The stress of admission in a nursing home must not be taken lightly.

Chapter 8
The relationship of cognitive impairment and cardiovascular risk factors with pain*

* submitted as: Achterberg WP, Scherder E, Pot AM, Ribbe MW. The relationship of cognitive impairment and cardiovascular risk factors with pain

Abstract

The relationship between cardiovascular risk factors (CRF) and the prevalence of pain was studied in this multi-centre, cross-sectional, observational study of newly admitted nursing home patients. It was hypothesized on basis of neuro-pathophysiological mechanisms that cognitively impaired residents with CRF would have more white matter lesions (probable vascular dementia), and would therefore experience more pain than those with cognitive impairment without CRF (probable Alzheimer dementia); probable Alzheimer dementia patients would experience less pain than cognitively intact patients.

562 patients (mean age 78.5, range 28-101, 64.6% female) were assessed by trained physicians using the Minimum Data Set (MDS) pain intensity and pain frequency items, and the Nottingham Health Pain profile (NHP) in 65 nursing homes in the Netherlands. Control variables (pain related diagnoses, Cognitive Performance Scale) were also measured with the MDS.

Cognitively impaired patients with CRF had a higher prevalence of pain (OR 2.08 -adjusted for gender, age and pain related disorders) than cognitively impaired patients without CRF but less pain than cognitively intact patients (adjusted OR 0.53). Cognitively impaired patients without CRF had significantly less pain than cognitive intact patients (adjusted OR 0.28). This study indicates that CRF, as a proxy for white matter lesions, is associated with more pain in cognitively impaired patients.

Introduction

It is important that clinicians appreciate the complex relations between dementia and pain, because pain is a treatable nuisance and a possible cause for behavioral disturbances (Geda & Rummans 1999). Understanding the differences in pain experience in different dementias might improve assessment and management. It is striking that so far only in one *experimental* pain study a relation between pain and neuropathology in demented patients has been described (Benedetti et al. 1999). They observed that, compared to elderly without dementia, patients with Alzheimer's disease (AD) showed an unchanged pain threshold but an increase in pain tolerance. An increase in pain tolerance implies that AD patients tolerate affective aspects of pain to a much higher level than elderly without dementia. The stability of the pain threshold and the increase in pain tolerance are consistent with the neuropathology of AD, i.e. a relative preservation of the primary somato-sensory area (Dickson 2001) and atrophy in areas that play a role in the motivational/affective aspects of pain (Scherder et al. 2003). The importance of relating neuropathology to pain in dementia has been emphasized in several studies (Scherder et al. 2003, Farrell et al. 1996, Huffman & Kunik 2000, Pickering et al. 2000). There is accumulating evidence that an alteration in pain experience depends on the presence of e.g. atrophy and white matter lesions (WMLs) which cause respectively a decrease or an increase in pain experience (Scherder et al. 2003). WMLs may disrupt connections between cortical areas and between cortical and subcortical areas (Mori 2002). The resulting deafferentiation might produce 'central pain', a symptom that has been observed after a stroke (Widar et al. 2002). Taken together, insight into the neuropathology underlying the dementia, in particular the presence of WMLs, might improve pain assessment in this population.

Identification of WMLs takes place by magnetic resonance imaging (MRI). MRI is however not a standard procedure within a nursing home setting. 'Indirect' measures for WMLs , which are easier to assess in a nursing home setting would therefore be very helpful in daily practice. The presence of cardiovascular risk factors like hypertension may be such a clinical proxy-measure for WMLs. Results of several studies indicate that subjects with cardiovascular risk factors like hypertension show significantly more WMLs than subjects without these factors (Pugh & Lipsitz 2002, Ylikoski et al. 2000, Kuo & Lipsitz 2004).

WMLs are associated with a decline in performance on a variety of cognitive tasks measuring executive functions, attention, psychomotor speed, speed of information processing, and visuoconstructive and spatial functions (Ylikoski et al. 2000, Junque et al. 1990, Desmond 2002). According to Desmond (2002), one mechanism underlying the decline in cognition is a disconnection of the thalamocortical pathway, by e.g. a lacunar infarction. Particularly the disconnection between the thalamus and cortex could cause central pain (Scherder et al. 2003). The suggestion that particularly the WMLs are responsible for the cognitive deterioration is supported by several studies. Patients with hypertension plus WMLs performed significantly worse on cognitive tests than hypertensive patients without WMLs (Swieten van et al. 1991, Schmidt et al. 1995). In other words, patients with cardiovascular risk factors (CRF) without cognitive impairment will probably not show WMLs whereas cognitively impaired patients with

CRF probably do have WMLs. This also suggests that cognitively impaired patients with WMLs probably have *vascular dementia*, and cognitively impaired patients without WMLs have probable *Alzheimer dementia.*

With respect to pain, this conclusion implies that the latter group of patients may report (an increase in) pain. In this paper CRF are used as a proxy for WML's. The main aim is to study the differences in pain prevalence in the following three groups: cognitively intact patients, cognitively impaired patients with CRF and cognitively impaired patients without CRF.

Patients and Methods

Design and sample:

There are 325 nursing homes with 53,800 beds in the Netherlands (26 per 1000 elderly people) (Ribbe et al. 1997). All nursing homes have specialized nursing home physicians in their staff (approximately 1 for every 100 patients). The subjects in this study are participants in an observational study among newly admitted nursing home patients. The data-collection was carried out by registered physicians in a specialist training program for nursing home physicians. This vocational training consists of two years of medical practice in a teaching nursing home with a one-day theoretical course per week at a University Institute for Nursing Home Medicine (Hoek et al. 2001). The present study was part of the research training, which is one of the elements of the core curriculum. The physicians included and assessed newly admitted residents within 10 days after admission in 65 nursing homes throughout the country. These homes all were connected to the specialist training program for nursing home physicians at the Vrije Universiteit University Medical Centre. The only exclusion criterion was being re-admitted after a temporary discharge (less than 90 days). The physicians were stimulated to include all admitted residents, but if this intervened with other curriculum activities, other *random* inclusion methods were allowed (e.g. the first 5 new admissions, or the first of every 5 new admissions). All assessments were performed between 13 January 1998 and 24 February 1999.

Patients

In total, 562 patients were assessed, 64.6 % was female. The mean age at admission was 78.5 (sd 10.5; range:28-101) which is a representative sample compared to the national average. Age was categorized in four categories for the logistic regression model; 7.5% was younger than 65 years, 17.1% between 65 and 74, 46.6% between 75 and 84, 28.8% was older than 84 years.

Measurement instruments

Most variables were derived from the Resident Assessment Instrument (RAI) Minimum Data Set (MDS) 2.0 items on nursing home care (Morris et al. 1990). These items have shown good reliability in several countries (Morris et al. 1997, Sgadari et al. 1997). Because the Dutch nursing home physicians in training were instructed in the RAI-MDS and they are on the ward on a daily

basis, they were expected to fill out the MDS themselves. Consultation of others however could take place.

Cardiovascular risk factors (CRF)

Risk factors for white matter damage as such are not well documented, but there are a number of logical cardiovascular antecedents (Gorelick 1997, Sachdev et al. 1999). The diagnoses used in this study for CRF were: Diabetes Mellitus, arteriosclerosis, peripheral vascular disease, hypertension, Transient ischemic attacks, stroke and hemipareses. Patients who had at least one of these risk factors were considered as being at risk for having WMLs.

Diabetes Mellitus was the most frequent cardiovascular risk factor (16.9%), followed by stroke (14.6%) and arteriosclerosis (14.6%); the other risk factors had a prevalence between 5 and 10 percent (see table 1). Of all patients, 261 (46.5%) had at least one cardiovascular risk factor and this was evenly distributed in the four age categories (χ^2 2 sided p= .493).

Patients with cognitive impairment who had at least one CRF are considered in this study as 'probable vascular dementia', and those without CRF as 'probable Alzheimer dementia'.

Table 1: Cardiovascular risk factors in 562 newly admitted nursing home patients

	cognitive (n=302)	**intac**	**cognitive (n=254)**	**impaired**	**All n=562#**
	n (%)		**n (%)**		**n (%)**
diabetes	46 (15.2)		48 (18,9)		95 (16.9)
arteriosclerosis	53 (12.6)		28 (11)		82 (14.6)*
peripheral vascula disease	19 (6.3)		9 (3.5)		28 (5)
hypertension	16 (5.3)		11 (4.3)		27 (4.8)
TIA	12 (4.0)		20 (7.9)		32 (5.7)
Stroke	41 (13.6)		40 (15.7)		82 (14.6)*
hemiplegia	35 (11.6)		15 (15.9)		52 (9.3)
≥ 1 risk factor					**261 (46.5)**

including 6 missing values CPS

*n=561

Pain related disorders

Patients who had one of the following diagnoses were considered as being at greater risk for having pain: arthosis/osteorthritis, hip fracture (with or without surgery), total hip, other fracture (e.g. upper arm), total knee, other (orthopaedic) surgery, osteoporosis, contractures and any malignancy (Finne Soveri et al. 2000, Proctor & Hirdes 2001). The presence of one of these disorders was used in multivariate regression analysis as a control variable.

Level of cognitive functioning

Cognitive functioning was measured according to the MDS-Cognitive Performance Scale (CPS), which is based on 5 MDS-items. The CPS is a seven-category index, ranging from cognitively intact to very severely impaired (Morris et al. 1994). It has shown substantial agreement with the Mini-Mental State Examination (MMSE) in the identification of cognitive impairment in research settings (Hartmaier et al. 1995). The index is dichotomized by combining the four severe categories as 'low' cognitive performance and the three other categories as 'high' cognitive performance (Mor et al. 1995).

Pain

Pain was assessed by two questionnaires.

The Nottingham Health (pain) Profile (NHP) (Hunt et al. 1980).

This is an eight item (yes/no) questionnaire. Of all 562 patients, 412 were able to answer the NHP questions. Reasons for not completing the NHP were: cognitive deficits (128), low consciousness (9), problems with hearing and reading (5), severe aphasia (21), other reasons (11), or more than one of these (22).

The MDS.

Pain was also measured using the MDS-item J2a (pain frequency) and J2b (pain intensity). For logistic regression analysis and Chi square analysis pain was dichotomized into never pain versus daily or less than daily pain. The accuracy of the measurement of pain with MDS items has been established in a large nursing home sample against a Visual Analogue Scale (Fries et al. 2001). Some studies have emphasized that using the MDS for pain detection could lead to underreport (Cohen-Mansfield 2004, Fisher et al. 2002). The correlation between the MDS pain frequency and the NHP in this sample was .678 (Pearson).

Analysis

The differences between the three groups *(cognitively intact*, *cognitively impaired but CRF absent* and *cognitively impaired CRF present*) were estimated in a logistic regression model in which pain was the outcome variable. We analyzed these relations in two models: one with the cognitively intact group as reference group and the other with the cognitively impaired/CRF- group as reference. Both models control for age, gender and having at least one pain related diagnosis.

Results

Pain

279 patients had no pain, 182 patients (32.4%) had daily pain, and 100 patients (17.8%) had less than daily pain according to the MDS. Pain intensity was mild for 113 patients (20.1%), moderate for 122 (21.7%) and at times excruciating for 47 (8.4%). According to the NHP, 53.2% had no pain, 14.6% had one positive pain item, and the other 32.3% had two ore more positive pain items. Pain was more prevalent in patients who had at least one 'pain related disorder' (60.2% versus 41.4%).

Cognition

Mean cognitive performance in the total group was 2.08, in the group without any CRF the cognitive performance was slightly better (2.01) than in those with at least one CRF (2.17), but this was not statistically significant (p= .336).

The majority of patients with relative intact cognitive performance (CPS 0-2, n=302) had pain: 185 (61.3%). In the cognitively impaired (CPS 3-6, n=254) group, 96 (37.8%) had pain (significance of difference: χ^2 $p < .001$).

Cardiovascular risk factors

Cognitively impaired patients with at least one CRF had more pain according to the MDS (45.4% had pain) than those who had no CRF, of whom 31.1% had pain (χ^2 p= < .001, see table 2). In cognitively intact patients, there was no significant difference for CRF status.

The logistic regression model showed that cognitively impaired patients without CRF had less pain then cognitively intact patients: odds ratio 0.28 (adjusted for age, pain related disorders and gender). Cognitively impaired patients with at least one CRF also had less pain than cognitively intact patients, (adjusted odds 0.59), but this group had significant more pain than the cognitively impaired patients without CRF: odds ratio 2.08 (adjusted for age, gender and having at least one pain related disorder (table 3).

Table 2: Patients with pain (according to the MDS) in 3 subgroups: *cognitively intact*, *Cognitively impaired and CRF present*, and *Cognitively impaired and CRF absent*

	Pain	**p (Chi square 2-sided)**
Cognitively intact (n=302)	185 (61,3%)	<. 001
Cognitively impaired and CRF present (n=119)	54 (45.4%)	
Cognitively impaired and CRF absent (n=135)	42 (31.1%)	

CRF: Cardiovascular Risk Factors

Table 3: Logistic regression models: Odds ratio's for having any pain according to the MDS for three different groups: *cognitively intact*, *Cognitively impaired and CRF present*, and *Cognitively impaired and CRF absent* (adjusted for age, gender and having at least one pain related disorder)

	Adj OR (95% CI)	**p**
Cognitively impaired and CRF present : cognition intact	0.59 (0.38-0.92)	.021
Cognitively impaired and CRF present: Cognitive impaired and CRF absent	2.08 (1.22-3.53)	.007
Cognitively impaired and CRF absent: cognition intact	0.28 (0.18-0.45)	< .001

CRF: Cardiovascular Risk Factors

Discussion

In the present cross-sectional observational study in which 562 newly admitted nursing home patients participated, the relation between cardiovascular risk factors (CRF), cognition, and pain is examined. The main finding of the present study is that patients with cognitive impairment and CRF have more pain than patients with cognitive impairment without CRF. Whereas all patients with cognitive impairment were found to have less pain, this difference was found to be stronger for cognitively impaired patients without CRF. These findings support our hypothesis that patients with (Alzheimer) dementia might experience less pain than cognitively intact patients, but (vascular) dementia patients with extensive white matter lesions (WML) experience more pain than those with no WML. The presence of WMLs in the group of 'probable vascular dementia' patients might well explain different pain experience, as they may disrupt the connection between the cortex and subcortex (Mori 2002), or between the secondary somatosensory cortex and the intralaminar thalamic nuclei (Schmahmann & Leifer 1992), resulting in an increase in pain (Scherder et al. 2003, Farrell et al. 1996).

One of the strengths of this study is that the relation between pain and cardiovascular risk factors was studied in a model that controlled for confounding mechanisms, like gender, age and pain related diagnoses. The prevalence of pain in this study was comparable to other studies, though higher prevalences have been reported (Ferrell et al. 1995). Other studies using the MDS have also found prevalence rates of approximately 50% (Proctor & Hirdes, Fries et al. 2001).

The complexity of pain assessment in elderly with cognitive impairment has been emphasized in several studies (Ferrell 1995). One of the main findings of clinical studies on pain in dementia is that demented patients are able to complete at least one of the available pain scales (Ferrell 1995). Pain scales include among others questionnaires, verbal rating scales, visual analogue scales, and faces pain scales (Wynne 2000). The administration of these scales requires an active participation of the patient. However, when the cognitive impairment increases, the reliability of the interaction with the patient will decline and more 'passive' pain assessments like autonomic responses to pain (Rainero et al. 2000) and pain observation (Manfredi et al. 2003) can provide valuable information. The pain instruments used in this study were an (MDS) observational scale and a perceived pain (NHP) questionnaire, based on self report. The latter could not be filled out in severe cognitively impaired patients (26.7% of all patients). In these patients the MDS pain items was the only measure for pain. The validity of the MDS pain data, especially in these cognitively impaired patients, heavily depends on the expertise of the raters (Fries et al. 2001). In non-research settings and with assessors which might have disputable knowledge of the patient disappointing reliability and validity results have been found (Cohen-Mansfield 2004, Fisher et al. 2002). In this study physicians performed the assessments, and the correlation with a pain self report scale was very much higher than in a non-research setting (0.68 versus 0.32) (Cohen-Mansfield 2004). Therefore, the pain data in this study seem to be more robust than in previous research with MDS pain items. Still, this study will have missed some patients in pain (especially in those with very severe cognitive impairments) which could have been detected with more elaborative instruments, like

visual analogue scales, and faces pain scales (Wynne 2002).

A broad range of risk factors was included in this study: diabetes mellitus, arteriosclerosis, peripheral vascular disease, hypertension, transient ischemic attacks, stroke and hemipareses. These clinical situations are very different in both the strength of the risk, as in the level of evidence of being a risk factor for white matter lesions. In the present analysis all of these risk factors were considered as equally important. This may have consequences for the generalizability of the results.

The relation between CRF, cognitive impairment and pain should be further explored by assessing the nature and extent of cognitive impairment and the extent and location of WMLs by brain imaging. Understanding how and why cognitive impairment and pain is related might help clinicians in recognizing, managing and perhaps even prevention of pain.

Chapter 9
Pain prevalence and management on different care wards *

* submitted as: Achterberg WP. Pot AM, Scherder E, Ribbe MW. Pain prevalence and management on different care wards among newly admitted Dutch nursing home residents

Abstract

Pain in the nursing home is highly prevalent. The assessment and management of pain in this setting has been shown to be suboptimal. Pain in dementia patients is an extra challenge, because of the specific assessment difficulties due to cognitive impairment. The prevalence and management of pain on different care wards (psychogeriatric, somatic and rehabilitation) was studied in 562 newly admitted Dutch nursing home residents. Pain was measured according to the Nottingham Health Profile (perceived pain) and the MDS pain observation items (frequency and intensity). Patients on psychogeriatric wards had less pain than patients on somatic wards, even when we controlled for possible confounders like age, gender, cognitive status, ADL, pain related disorders and depression: OR 0.45 (95% CI: 0.27-0.75). Patients on psychogeriatric wards also received less pain medication, controlled for having pain: OR 0.37 (95% CI: 0.23-0.59) compared to the somatic ward. We conclude that admission on a psychogeriatric care ward, independent of cognition, is associated with lower recognition and treatment of pain.

Introduction

Pain is highly prevalent in nursing homes (45-80%) and it has a serious impact on quality of life and functional impairment (Ferrell 1995). There is an increase in pain related pathology with advancing age, and although this could mean older people *experience* more pain, they appear to *report* less pain (Frampton 2003). There are several factors that have an influence on experience and report of pain, like mood state, perception of control, expectations, and social or cultural conditions (Turk & Okfuji 1995). The presence of dementia is even more complicating in the assessment of pain, because the neuropathology changes related to dementia may also influence the pain threshold and experience. There is accumulating evidence that patients with *Alzheimer's disease* (AD) have an unchanged pain threshold but an increase in pain tolerance (Benedetti et al. 1999). This is consistent with the neuropathology of AD, i.e. a relative preservation of the primary somato-sensory area (Dickson 2001) and atrophy in areas that play a role in the motivational/affective aspects of pain (Scherder et al. 2003). The neuropathology of *vascular dementia* leads to an increase in pain experience (Farrell et al., 1996; Scherder et al., 2003), through disruptions of the connection between the cortex and subcortex (Mori 2002), or between the secondary somatosensory cortex and the intralaminar thalamic nuclei (Schmahmann & Leifer 1992). Another difficulty in the assessment of pain in dementia patients is that the validity of the instruments is difficult to establish (Huffman & Kuni 2000, Manfredi et al. 2003, Ferrell et al. 1995).

The issue of *pain management* in nursing homes has received little attention in research. Although there are specific problems in this population, like sensitivity to side-effects of drugs, consensus is that good pain management is very well possible, but often inadequate (Ferrel 1995). Pain management in dementia patients is assumed to be even worse because of communication and detection difficulties, and the fear of inducing side-effects and polypharmacy (Frampton 2003). Earlier studies suggest that Alzheimer patients generally receive less pain medication (Scherder et al. 1997).

More insight into factors that influence the assessment and management in dementia patients is necessary (Ferrel et al. 1995, Frampton 2003). One of these factors might be the environment. Assessment and management of pain in pediatrics can be improved when the attention is simultaneously on individual caregivers and environmental factors like ward and institution (Jordan-March et al. 2004). Several interventions on different levels were introduced at the same time in this study: the introduction of a pain assessment tool, a change in drug prescription policy, education, and multidisiciplinary rounds.

Residents with dementia in the Netherlands are admitted on specialized psychogeriatric wards and residents with other diseases are often placed on separate long term care, palliative or rehabilitation wards. These specialized psychogeriatric wards are comparable to the Special Care Units (SCU) for Alzheimer disease in the USA. These SCUs have special attention for behavioral interventions while minimizing the use of psychotropic medication and restraints. It is unknown

what the quality of pain assessment and pain management is compared to other nursing home facilities with a more physical oriented care (Gerdner & Beck 2001, Kane et al. 1998, Warren et al 2001, Lane et al 2003).

This study compares the prevalence of pain and pain-management on three different wards (rehabilitation, psychogeriatric and somatic) in a cross-sectional sample of newly admitted nursing home patients.

Patients and Methods

Design and sample:
There are 325 nursing homes with 53,800 beds (26 per 1000 elderly people) in the Netherlands (Ribbe et al 1997). All nursing homes have specialized nursing home physicians in their staff (approximately 1 for every 100 patients). The subjects in this study are participants in an observational study among newly admitted nursing home patients. The data-collection was carried out by registered physicians in a specialist training program for nursing home physicians. This vocational training consists of two years of medical practice in a teaching nursing home with a one-day theoretical course per week at a University Institute for Nursing Home Medicine (Hoek et al. 2001). The present study was part of the research training, which is one of the elements of the core curriculum. The physicians assessed newly admitted patients. Patients who were re-admitted after a temporary discharge (less than 90 days) were excluded.

Patients
562 patients were assessed, 64.6 % were female. The mean age at admission was 78.5 (sd 10.5; range: 28-101) which is a representative sample compared to the national average (Arcares 1999). Age was categorized in four categories for the logistic regression model; 7.5% was younger than 65 years, 17.1% between 65 and 74, 46.6% between 75 and 84, 28.8% was older than 84 years.

Ward type
All patients were defined as admitted on a somatic ward (n=129; 32.0%), psychogeriatric ward (n=247; 44.0%), rehabilitation ward (n=129; 23.0%), or other (n=5; 1.1%). Two dummy variables were constructed: one for psychogeriatric ward and one for rehabilitation ward, both with the somatic ward as reference category. This sample had more patients admitted on psychogeriatric wards (44%) than the national average in that year, which was 33.6% (significance of the difference $p < .001$) (Arcares 1999). There are no national data available on the other types of ward described.

Measurement instruments
Most variables were derived from the Resident Assessment Instrument (RAI) Minimum Data Set (MDS) 2.0 items on nursing home care (Morris et al.1990). These items have shown good reliability in several countries (Hawes et al.1995, Morris et al. 1997, Sgadari et al.1997). Dutch

nursing home physicians are on the ward on a daily basis; they received instructions and filled out the MDS themselves, however consultation of others could take place.

Pain related disorders

Patients who had one of the following diagnoses were considered as being at greater risk for having pain: Arthosis/ostearthritis, hip fracture (with or without surgery), total hip, other fracture (e.g. upper arm), total knee, other orthopedic surgery, osteoporosis, contractures and any malignancy (Finne-Soveri et al. 2000 Proctor & Hirdes 2001). The presence of one of these diagnoses was used in multivariate regression analysis as a control variable. The distribution of these pain related disorders for the different ward types are shown in table 1.

Level of cognitive functioning

Cognitive functioning was measured according to the MDS-Cognitive Performance Scale (CPS), which is based on 5 MDS-items. The CPS is a seven-category index, ranging from cognitively intact to very severely impaired (Morris et al 1994). It has shown substantial agreement with the Mini-Mental State Examination (MMSE) in the identification of cognitive impairment in research settings (Hartmaier et al. 1995). The index is dichotomized by combining the four severe categories as 'low' cognitive performance and the three other categories as 'high' cognitive performance (Mor et al. 1995).

Table 1: distribution of pain related disorders diagnosis on different wards

Active diagnosis	**Somatic ward (n=181)**		**Psychogeriatric ward (n=247)**		**Rehabilitation ward (n=129)**	
	n	%	n	%	n	%
Arthosis/ Osteoarthritis	23	12.7	32	13.0	20	15.5
Hip fractures no surgery	0		1	.4	0	
Hip surgery	4	2.2	8	3.2	7	5.4
Total hip	0		1	.4	6	4.7
Total Knee	2	1.1	1	.4	6	4.7
Other fracture	7	3.9	6	2.4	4	3.1
Other accident	3	1.7	4	1.6	1	.8
Osteoporosis	9	5.0	10	4.0	7	5.4
Contractures	9	5.0	8	3.2	1	.8
Other surgery/orthopaedic	4	2.2	4	1.6	4	3.1
Any malignancy	14	7.7	11	4.5	4	3.1

Pain

Pain was assessed by two questionnaires.

-*The Nottingham Health (pain) Profile (NHP)* (Hunt et al 1980).

This is an eight item (yes/no) questionnaire. 412 (out of the 562) were able to answer the NHP questions. Reasons for not completing the NHP were: cognitive deficits (128), low consciousness (9), problems with hearing and reading (5), severe aphasia (21), other reasons (11), or more than one of these (22).

-*The MDS.*

Pain was also measured using the MDS-item J2a (pain frequency) and J2b (pain intensity). Pain was dichotomized into never pain versus daily or less than daily pain for logistic regression analysis and Chi square analysis. The accuracy of the measurement of pain with MDS items has been established in a large nursing home sample against a Visual Analogue Scale (kappa .707) (Fries et al 2001).

Some studies have emphasized that using the MDS for pain detection could lead to underreport (Fisher et al 2002, Cohen-Mansfield 2004). The correlation between the MDS pain frequency and the NHP in this sample was .678 (Pearson)

Analysis

Chi-square statistics and multivariate logistic regression models were used to analyze differences between the care wards. First, unadjusted regression analysis was performed, then we adjusted for pain related diagnosis and finally we performed additional adjustment for demographics, ADL, mood and cognition (SPSS 10.1).

Results

Prevalence of pain on different wards,

According to the NHP (n=412), 46.8% of residents had any pain, according to the MDS (n=561) 50.3%. Arms and legs, back, joint and hip were the most frequent locations of pain (see table 2): more than 10% of residents had pain in one of those places.

Perceived pain, pain intensity and pain frequency scores were significantly lower on psychogeriatric wards. More specifically, on the somatic wards 61.7% had any pain according to the MDS. (53.9% according to the NHP), on psychogeriatric wards 33.6% (27.1% according to the NHP) and 65.9% (57.8% according to the NHP) on rehabilitation wards ($\chi^2 = 49.387$; $p < .001$) These differences were more distinct for daily pain, then for less than daily pain (see table 4).

The unadjusted Odds Ratio (logistic regression analysis) for having pain on a psychogeriatric ward was 0.32 (95% CI 0.21-0.47) compared to having pain on a somatic ward. The strength of the relation did not change when the model controlled for cognitive impairment,: OR 0.35, 95%

CI: 0.22-0.56). The relation also did not change, when in the final adjustment we additonally controlled for having at least one diagnosis that can contribute to pain, age, gender, ADL, and depressive symptoms (see table 4).

Table 2: Location of pain

Location of pain	n	%
Back	69	12.3
Bone	30	5.3
Thorax	7	1.2
Head	28	5
Stomach/abdomen	25	4.4
Pelvis	13	2.3
Hip	58	10.3
Joint	64	11.4
Arms and legs	80	14.2
Surgical wound	23	4.1
Soft tissue	48	8.5
Phantom pain	5	.9
Other place	42	7.5

Pain management/Medication use

351 residents (62.5%) received no pain medication at all, 196 (34.9%) used non-opoid pain-medication, 36 (6.4%) received opoid medication; 21 residents (3.7%) received opoid and non-opiod medication, and 190 (33.8%) opoid or non-opiod medication.

There was a strong relation between the presence of pain measured with the MDS and the use of medication (Spearman rho = 0.475, $p < .001$, for pain measured with the NHP this was 0.389, $p < .001$)

Table 3: Distribution of perceived pain according to the NHP for different type care wards

	Somatic ward (n=152) (84.0% of total)		Psychogeriatric ward (n=129) (52.2% of total)		Rehabilitation ward (n=128) (100% of total)		All (n=412) (73.3 of total)*	
	N	%	n	%	n	%	n	%
At night	39	25.7	3	2.3	33	25.8	75	18.2
Unbearable pain	15	9.9	0	0	5	3.9	20	4.9
Change position	52	34.2	18	14.0	45	35.2	117	28.4
Walking	30	19.7	18	14.0	46	35.9	95	23.1
Standing	31	20.4	13	10.1	34	26.6	79	19.4
Walking stairs	26	17.1	4	3.1	17	13.3	47	11.4
Constant pain	26	17.1	2	1.6	9	7.0	16	3.9
Sitting	36	23.7	3	2.3	28	21.9	67	16.3
Mean NHP (sd)	1.53 (1.8)		0.47 (1.0)		1.70 (1.9)		1.25 (1.72)	

*including 5 from other types of wards

Table 4: Pain frequency on different ward types

	No pain n (%)	less than daily pain	daily pain	total
Somatic	69 (38.3)	34 (18.9%)	77 (42.8%)	180
psychogeriatric	164 (66.4)	37 (15%)	46 (18,6)	247
rehabilitation	44 (34.1)	28 (21.7)	57 (44.2)	129
Total	277 (49.8)	99 (17.8)	180 (32.4)	556

Table 5: The Odds ratio for having pain according to the MDS on different care wards, adjusted for cognition, sex, age, ADL, pain related diagnosis and depression (logistic regression model)

Pain	Adj OR*	95% CI	p
Somatic ward (reference group)	-	-	.001
Psychogeriatric ward	0.45	0.27-0.75	.002
Rehabilitation ward	1.29	0.77-2.17	.337

(*Adjusted for cognition, sex, age, ADL, pain related diagnosis and depression)

Somatic patients had a mean of 2.83 days per week non-opoid pain medication, 1.13 for psychogeriatric and 3.31 for rehabilitation patients (p< .001).

The mean number of days per week opoid medication was 0.11 for psychogeriatric, versus 0.71 for somatic patients (p < .001).

60% of residents with any pain received pain medication, opoid or non-opoid. For residents with high cognitive performance this was 60.9%, for residents with low cognitive performance 55.8%. On the somatic wards, 67.7% of patients with pain received any pain medication, on the rehabilitation wards 70.6%. On the psychogeriatric wards 39.8% of patients with pain received any pain medication (table 6).

Table 6: % of patients on a ward with or without pain that receive any pain medication (opoid and/or non-opoid)

	% receiving any pain medication	
	Patients without pain	**Patients with pain**
Somatic	20.3	67.6
Psychogeriatric	10.4	39.8
Rehabilitation	18.2	70.6

In a multivariate logistic regression model, patients on psychogeriatric wards had significantly less pain medication compared to residents on a somatic ward, even when we controlled for the presence and intensity of pain (OR: 0.41, 95% CI 0.25-0.67, p< .001,Table 7).

Table 7: The Odds ratio for receiving pain medication on different care wards, controlled for MDS intensity of pain (logistic regression model)

	Adj OR*	**95% CI**	**p**
Somatic ward (reference group)	-		< .001
Psychogeriatric ward	0.41	0.25-0.67	< .001
Rehabilitation ward	1.15	0.68-1.94	.596

*adjusted for MDS pain intensity

Discussion

This study found that half of all newly admitted Dutch nursing home residents have any pain, according to both an observational (MDS) and a perceived (NHP) pain scale. This prevalence is in concordance with other studies in nursing homes, although some studies found even higher prevalence rates (Ferrel 1995). Patients on psychogeriatric wards had less pain than patients on somatic or rehabilitation wards. This relation was strong (Odds Ratio 0.45 compared to somatic ward) and expected, as it is known that cognitive impairment could be associated with less pain (Frampton 2003). However, the decrease in pain experience on psychogeriatric wards was not explained by the level of cognitive functioning or by differences in demographics or mood. These findings suggest that other influences are important factors in the prevalence or detection rates of pain. We can only speculate on the explanatory mechanisms responsible for the differences found in this study between nursing home patients of different ward types. In addition to possible disease related differences (e.g. in dementia), there are several environmental differences, like physical environment, activity patterns and care provision. Pain might indeed be less prevalent on psychogeriatric care wards, because there may be more attention for the role of a friendly, more home-like environment. Possibly this leads to less stress, which may lead to a change in pain perception or pain threshold. Pain may indeed be less prevalent on psychogeriatric care wards if the majority of the patients suffer from AD; results of previous studies have shown that a number of AD patients indicate to suffer from less pain than elderly without dementia (Marzinski et al. 1991). On the other hand, patients with vascular dementia may report an increase in pain experience (Farrell et al. 1996; Scherder et al. 2003) which should alert the nursing staff that pain is a clinical symptom that needs attention and treatment. Pain may present itself in a different way which might lead to a lower 'index of suspicion' (Frampton 2003).

Pain might also be presented on a different way, for instance not as pain but as behavioral disturbances (Geda et al. 1999).

Patients admitted on psychogeriatric wards had less pain medication, something that has been found in an earlier study (e.g. Scherder et al. 1997). This study also showed that receiving less medication was not explained by the presence or intensity of pain. This suggests that next to the *detection*, the *reaction* of physicians and nurses on pain is influenced by the environment: on rehabilitation wards pain is more prevalent, and there are few residents in pain who do not receive pain medication. On the other hand, on psychogeriatric wards pain is apparently not so prevalent, and maybe therefore the inclination to give pain medication is smaller. One of the strengths of specialized psychogeriatric wards is that they are generally more likely to aspire to fewer medications, especially for behavioral problems (Kane et al. 1998). This could have a negative impact on the quality of pain management. Education and information on pain recognition and management for nurses and physicians, especially those who work with dementia patients, could then be appropriate. The social ecology model states that in changing behavior the likelihood of success increases when one not only focuses on changing different

levels, usually described as *Downstream* (individual level: e.g. education, motivation), *Mainstream* (e.g. ward and institutional changes) and *Upstream* (society: e.g. public policy and national guidelines) (Smedley & Syme 2001). An example of a successful intervention based on this model showed improved pain assessment and management in pediatrics (Jordan-Marsh et al 2004).

This was a study on recently admitted nursing home patients, and both the detection and management differences we found could represent not the quality of care on the nursing home ward, but the quality of the care setting before admission (e.g. hospital or primary care). In Dutch nursing home care, it is expected of the nursing home physician to perform a physical assessment and draft a preliminary care plan together with the responsible nurse within 2 working days after admission. Therefore, on these theoretical grounds we believe the assessment and management of pain reflects the situation on these nursing home wards. To confirm this, we performed post hoc analysis in which we controlled for being admitted from a hospital: this did not change the relations between the type of ward and the prevalence of pain and the relation with medication. Future research with patients who are admitted for a longer period is the only way to confirm our findings and hypothesis.

The MDS pain items have shown adequate to excellent reliability in research settings. We used a validated measure for perceived pain (Nottingham Health Profile) in addition to the MDS Pain items. Questions have been raised in the past about the validity of the MDS pain items. This was based on the weak relation between the MDS pain items and the use of analgesic medication in that study (Fischer et al 2002). In this sample, the relation was high. In addition, this study showed a much higher relation of the MDS pain items with a perceived pain scale than has been found in another study (Cohen-Mansfield 2004). Thus, the validity of our observational pain data, collected by trained physicians, seems to be adequate, at least for the not severely cognitive impaired patients.

This study focused on newly admitted patients, and the findings might be different for patients who become long term residents. This was a cross-sectional study, and therefore no claims on the causality of relations can be made. It is possible that other factors on which we have no data are responsible for the different pain prevalence and management ratios on psychogeriatric wards. Especially psychological or psychosocial factors, like personality, beliefs, stress, coping mechanisms and social support are not represented in this study (Zaza & Baine 2002, Lewandowski 2004). This study prompts further research into the role of the environment, including activities, physical environment and care givers attitude in the assessment and management of pain in the nursing home.

Chapter 10
General discussion and summary

This chapter summarizes the main findings for each of the research questions. Subsequently, some methodological and theoretical considerations are discussed. In addition, recommendations are suggested for both nursing home care and nursing home research.

Introduction

Nursing homes care for frail elderly patients. Patients may need help with ADL (Activities of Daily Living, like washing, and clothing) and may require supervision, support and treatment on other domains, because of sensory, psychological and social needs. They are my patients, and my motivation in nursing home medicine and nursing home research is to improve the quality of care in nursing homes and the quality of life of my patients, and it is also the motivation for this thesis.

To meet the complex multi-domain needs of (nursing home) patients it is of paramount importance that these needs are assessed. The scientific knowledge of patient assessment and its effect on quality of care and quality of life in The Netherlands has been poor (Wendte & Danse 1994, Sluijs et al. 1993). A review on the literature on multi-dimensional assessment instruments concluded that many authors recognize the need for such instruments. However, this has resulted in very few publications presenting validated and reliable multi-dimensional instruments. The Minimum Data Set of the Resident Assessment Instrument (MDS-RAI) was by far the most extensively tested and evaluated instrument (see also Holtkamp 2003). This is the reason that the MDS-RAI has a central position in this thesis.

Part I: The MDS-RAI instrument

The Resident Assessment Instrument (RAI) for nursing home care has been developed as an answer to concerns about poor quality of care in nursing homes in the United States. Its goals are to improve the quality of care and quality of life in nursing homes (Morris et al. 1990). The RAI consists of a structured screening questionnaire (the Minimum Data Set MDS), an algorithm that links the information from the MDS to certain important problem areas, and protocols (Resident Assessment Protocols, RAPs) for further analysis of these problem areas. The MDS has items concerning many domains of physical, mental and social functions. It requires observations, interviews and clinical assessment. The full MDS is conducted at admission and yearly thereafter. Between these full assessments a quarterly review is filled out, which is a condensed version of the full MDS. When a resident has an important change in health status on any other point in time, a full MDS assessment is performed again. Certain scores in the MDS trigger specific protocols, the RAPs. There are 18 RAPs, which give directives for further analysis and handling of major problem areas in nursing home care. The RAI therefore links structured, individual assessment information to care planning of that resident, which should lead to 'tailor-made' care.

The RAI Manual contains definitions of MDS-items, guidelines to fill out the MDS, the RAPs, practical guidelines for taking a case history, for observations, for communication between caregivers and for the making of a care plan are described in (Morris et al. 1991, Morris et al. 1995, Morris et al. 1996).

Main findings

Research Question 1 (Chapter 2):

Is the MDS-RAI for nursing home care a reliable and valid instrument for care planning and research in nursing home care?

Chapter 2 is the result of a literature search on the MDS-RAI and its psychometric properties: Reliability and validity.

The studies on interrater reliability show international differences. The kappa for mood in Japan is 0.45, and in Switzerland 0.93 (Sgadari et al. 1997). The research design probably played a part in these differences in addition to cultural and environmental differences. In Switzerland, the second assessment was on the same day, while in Japan the second assessment was after 14 days. The number of assessments in the studies differed significantly (between 14 and 129).

Most MDS items achieve good reliability (kappa $\geq$ 0.6), and 1/3 of the items excellent (kappa $\geq$ 0.8) reliability in the latest version (MDS 2.0), and also in regular care settings (Morris et al. 1997,

Casten et al. 1998). However, there are some divergent results, especially in psychosocial areas, such as mood and behavior (Casten et al. 1998). There are several explanatory factors. The considerable heterogeneity of the results over the different facilities is noteworthy for almost all studies using multiple facilities (Crooks et al. 1995, Mor 2004). The training of the assessor, the setting (research or regular care) and proximity to the resident (involved in actual care giving) may be the prime explanations for these differences (Schnelle et al. 2001, Engle et al. 2001). The level of cognitive performance, and thus the study population, also influences the reliability of most items (Stineman & Maislin 2000, Gerritsen et al. 2004, Snowden et al. 1999, Phillips et al. 1993).

The validity is not identical for all parts of the MDS. ADL and cognition have good validity, but (similar to the reliability) mood and behavior validity is subject to different results and views (Lawton et al. 1998). In one, although small, sample, the MDS-depression rating scale (MDS-DRS) performed better (more sensitive and more specific) than the Geriatric Depression Scale (GDS) (Burrows et al. 2000). In another study, the MDS-DRS was found to have acceptable specificity but low sensitivity, compared with the GDS and Hamilton depression rating scale (Anderson et al. 2003). In that study, the internal consistency of the MDS-DRS was low (Cronbach Alfa: 0.67) - for instance much lower than in our study (0.87-see chapter 7). This raises questions about the reliability of the Anderson data. Recently, the psychometric properties of several MDS based observational scales in the Netherlands were reported (Gerritsen et al. 2004). The MDS ADL hierarchical scale and MDS Cognitive Performance Scale (CPS) performed excellently: mean intrarater and interrater reliability of the items had a kappa $\geq$ 0.78, intra- and interrater intraclass correlation coefficients $\geq$ 0.80, internal consistency $\geq$ 0.74. The reliability of the MDS Depression Rating Scale (DRS) was lower than that of the ADL and CPS, but nonetheless encouraging: mean intrarater and interrater reliability of the items kappa 0.50, intra- and interrater intraclass correlation coefficients $\geq$ 0.71, internal consistency was 0.73 (Gerritsen et al. 2004).

Two other studies concluded that their incongruent findings on the MDS depression indicators may reflect the assessment process: The practice of non-direct caregivers completing the MDS, or 'assessment nurses' hired to take the responsibility for 'paper compliance' (Schnelle et al. 2001, Engle et al. 2001)

The conclusion based on this review of the literature is that assessment with the MDS-RAI for nursing home care can produce reliable and valid data for both patient care and research. However, one should bear in mind that there have been facilities and circumstances in which it has produced less reliable and valid data, for example when the assessment is solely carried out to comply with a federal mandate.

If MDS-RAI data is used for research, then one has to ensure that all participating facilities feel responsible for providing high quality data. It has been shown that 25% of the facilities in the USA had inadequate reliable pain items, whereas ADL measures were reliable in almost all

facilities (Mor 2004). This is a serious problem for research with MDS data in thousands of facilities (Teno et al. 2004).

Research Question 2 (Chapter 3):

Can MDS-items be used to create a valid scale for behavior based on the Social Production Functions (SPF) theory?

Reliable and valid assessment data are helpful for care planning. Specific outcome measures, which summarize the patients functioning in a specific domain, are perhaps even more important for care planning. Furthermore, they are indispensable for epidemiological studies (Mor 2004). There are several outcome measures or scales within the MDS: For instance for ADL (Morris et al. 1999), cognition (Morris et al. 1994), depression (Burrows et al. 2000) and social engagement (Mor et al. 1995). Although there have been attempts to create a behavior scale from the MDS items (the unsettled behavior scale, mentioned in the paper by Phillips et al. 1997), this has not find its way into research or nursing home practice. When Dutch nursing home staff encountered the MDS-RAI, they commented on the need for such an instrument (Achterberg & Frijters 2003). This was the motivation to construct a reliable and valid behavioral scale (the Challenging Behavior Profile-**Chapter 3).** This scale is constructed using the insights of the Social Production Functions (SPF) theory. According to the SPF theory, resident behavior takes place in a social context, and social interaction has to do with the fulfillment of needs (Lindenberg 1996). Every individual is, to some degree, dependent on others to achieve *well-being*. In nursing home residents, this dependency is much stronger.

If the resident displays 'inappropriate' behavior (like conflict or repetitive behavior), this may evoke irritation, frustration and rejection from staff, family and other residents (Cohen-Mansfield et al. 1989). This could have a negative influence on their (staff, family other residents) willingness to fulfill her well-being goals. In other words: the resources to fulfill her well-being are *challenged*. The name '*Challenging Behavior Profile'* is preferred to *agitated*, *inappropriate* or *problem* behavior, which all have negative connotations.

Five clinical experts have selected MDS items, which concern resident behavior that may evoke reactions such as irritation, frustration and/or rejection from the (nursing) staff, other residents and/or visitors. This would, according to the SPF theory, undermine their willingness to fulfill the resident's needs with regard to well-being. Exploratory factor analyses of a sample of 656 nursing home residents yielded a 15-item scale, the Challenging Behavior Profile (CBP), which contains four internally consistent and valid sub-scales. These subscales measure conflict behavior, withdrawn behavior, restless and repetitive behavior, and claiming behavior. They were tested against the Behavior Rating Scale for Psychogeriatric Inpatients (GIP), an

observational behavior scale that is widely used and of known reliability and validity in Dutch long-term care facilities (Verstraten, 1988).

Internal consistency of the overall scale was 0.78 (alpha). The internal consistency of the new subscales ranged between 0.53 and 0.78. Overall inter-rater reliability of the items was 0.53 (Kappa), and it was 0.75 for the scale (ICC).

Our results suggest that the CBP can be used both for nursing home residents with and without dementia: the strength of the correlations with the comparison scales was similar for both groups. The application of the CBP may be helpful in improving the understanding of nursing staff and other caregivers why this behavior is an important threat to the residents' well-being, and why it is important to measure, and also, of how their own actions can play an important role in limiting the effect of the behavior on social well-being. This scale is available for all long-term care facilities using the MDS, and it can be used without additional assessment, because the items are included in the MDS. This is a huge advantage in times of staff shortages. However, it goes without saying that this screening does not replace professional assessment and management by a psychologist or psychiatrist. The suggested behavior profile with the items of the MDS-RAI helps the caregiver to ameliorate the circumstances and to improve the resources of the resident.

The negative relationships of the new (sub-) scales to social engagement that we found in this study are an indication that the behavior that we call 'challenging' does indeed has a negative impact on social well-being. This is in agreement with the ideas of the Social Production Functions, which states that behavior takes place in a social context, and social interaction has to do with the fulfillment of needs. It also stresses the need for regular behavioral assessment. The concluded is that the CBP may offer an important contribution to the existing clinical MDS scales.

Part II: quality of care after implementation of the MDS-RAI

Research Question 3 (Chapter 4):

What are the effects of the implementation of the MDS on the quality of care and patient functioning in nursing homes?

This chapter is a review of the literature on the effects of the MDS-RAI. The results show that the most important effects are found in indicators of the care process, such as the quality of the care plan: More comprehensive, more complete, better information (Dorman-Marek et al. 1996, Hawes et al. 1997, Ikegami et al. 1998). Additional studies confirmed this (Hansebo et al. 1998, Hansebo et al. 1999).

Considering health and functioning, the MDS-RAI method appears to have had the most positive effects in the USA on the most impaired residents, because they declined less rapidly in function (Phillips et al. 1997). Dehydration had a lower prevalence after RAI-implementation (2% pre-implementation versus 1% post-implementation), and the same applied for 'static ulcers' (which showed a decline from 4.5% to 3%). However, the prevalence of 'daily pain' was higher after implementation (13.4% pre versus 17% post) (Fries et al. 1997). The USA studies (Fries et al. 1997, Phillips et al. 1997, Hawes et al. 1997) were based on a non-controlled design. The study used an interrupted time series design with large representative cohorts. Although this is a powerful approach it is difficult to attribute the observed (positive or negative) effects to the implementation of the MDS-RAI because there are no control groups. Other influential (demographic and OBRA '87* related) processes also took place during the research period (Schnelle 1997). One could also argue that it is not clear whether a higher prevalence of some conditions is a good or bad outcome: Good assessment may lead to higher measured prevalence of many conditions (for instance pain and depression, see: Schnelle et al. 2001). However we cannot blame the researchers: The MDS-RAI was nationally implemented, so a randomized controlled trial in the USA was impossible. This has stimulated the research described in the next chapter. A non-randomized controlled trial on the effects of implementation of the MDS-RAI was performed in Dutch Nursing homes. The studied effects were quality of nursing care (this thesis) and health and quality of life (Holtkamp 2003). That study found very little effects on health and quality of life and this was probably due to methodological problems (see next chapter) (Holtkamp 2003).

* Omnibus Budget Reconciliation Act of 1987 or OBRA '87 creates a set of national minimum standards of care and rights for people living in certified nursing facilities.

Research Question 4 (Chapter 5):

Does the implementation of the MDS-RAI method improve the quality of the co-ordination of nursing care in Dutch nursing homes?

As was seen in the previous chapter, the implementation of the MDS-RAI is first of all expected to improve the quality of care, the care process and the care plan. Therefore, we performed a controlled trial to measure the effects of the implementation of the MDS-RAI in nursing homes.

Several aspects of co-ordination of nursing care were measured before and after implementation in 9 MDS-RAI wards, and 9 control or comparison wards in the Netherlands. Comparison wards were recruited from the same nursing home or comparable other 'matched' nursing homes. For this matching, a questionnaire was used which contained 40 items about facility characteristics, organisation and care services.

The measurements were done one month before and 8 months after MDS-RAI-implementation. Out of the 278 somatic patients that could be measured at the first data collection, only 175 patients could participate at the second, because of a high mortality rate in both control and MDS-RAI wards.

We found that the MDS-RAI was not implemented as planned on any of the wards: There were less MDS assessments and analyses with the RAPs than planned. This incomplete implementation was due to staffing and software problems.

A significant improvement after the implementation of the MDS-RAI was found on the subscale for case history, which proves that the MDS-RAI definitely inspires nurses to get more and better information from the resident. Improvements in the MDS-RAI nursing homes were also found for the care plan and all the other aspects of co-ordination of care, when compared to non MDS-RAI wards. However, these improvements were smaller and not statistically significant. The effects were partly due to a decrease in the quality of co-ordination of care in the control wards. The fact that there was no decrease of quality of care on MDS-RAI wards suggests that implementation of the MDS-RAI protects a facility against effects of staff-shortages on quality of care. The results are in line with the results of the US, Japanese and Swedish studies, which all found improvements in the process of care, especially in the comprehensiveness of the assessment and the content of the care plan (Dorman-Marek et al. 1996, Hawes et al. 1997, Ikegami et al. 1998, Hansebo et al. 1998, Hansebo et al. 1999)

The MDS-RAI is capable of improving the quality of care in nursing homes, but implementation in the Netherlands has been sub-optimal. Will individual residents benefit from this improvement? We found that the use of the MDS-RAI has led to better case history and better care plans, which suggests that the residents' needs are better assessed. The positive effects of the MDS-RAI on care process quality are likely to be an important stimulus to improve aspects of quality of life, well-being and health outcomes (Schnelle 1997). It is a first step towards

improving quality of life (Holtkamp et al. 2000, Holtkamp 2003). However, it has been difficult to measure these effects until now. The studies performed in the USA lacked control groups, and measures for perceived quality of care. Therefore, it was difficult to attribute changes to the MDS-RAI alone (Fries et al. 1997, Phillips et al. 1997, Ouslander 1997). The Dutch study on health and quality of life did have a control group, but suffered from a high attrition rate, because of high mortality in both MDS-RAI and control wards while the implementation was hampered by staff-shortages and software problems (Holtkamp 2003). The gap between perceived needs by the residents and the nursing care that was supplied diminished moderately in that study (Holtkamp et al. 2001).

Part III: insight in patient functioning using MDS-data

The third part of this thesis focuses on (epidemiological) studies with assessment data which have been obtained from nursing home patients with the MDS-RAI.

Relationships between different functions and disorders are often complex, and not fully understood in nursing home patients, because of their extensive co-morbidity (Fried & Guralnik 1987, Miller et al. 2000).

This thesis is focused on three problem areas: Depressive symptoms, pain and low social engagement. These are serious, highly prevalent and 'difficult to manage' conditions and they provide a major challenge for long term care settings like nursing homes (Ferrel 1995, Mor et al. 1995, Rovner et al. 1991). All three conditions are multi-factorial in origin and they can all have effects on several aspects of health and quality of life.

All four chapters use data of 562 newly admitted nursing home residents (psychogeriatric, somatic and rehabilitation) in 65 nursing homes in the Netherlands. Registered physicians, in training to become nursing home physician, collected the data. The physicians were stimulated to include all admitted residents, but if there were many new admissions or if inclusion intervened with other curriculum activities, other *random* inclusion methods were allowed (e.g. the first 5 new admissions, or the first of every 5 new admissions). All assessments were performed between 13 January 1998 and 24 February 1999.

The studies were performed on a very heterogeneous population: patients with all functional and cognitive levels, ages, and different health status were included, just as different goals of care were included: rehabilitation, palliative care and (somatic and psychogeriatric) long term care. The population was only homogenous in their length of stay in the nursing home: between 7 and 14 days. This was done because the assumption was that one of the most important assessments is performed at admission.

Research Question 5 (Chapter 6):

What are the effects of depression on social engagement in newly admitted Dutch nursing home residents?

Social engagement is the ability to respond adequately to social stimuli in the social environment: To participate in social activities and interact with other residents and staff, or to set one's own goals. It is about initiative and involvement. It this chapter, the hypothesis was tested that depressive symptoms hamper the newly admitted residents' ability to be socially engaged. Depressed residents are likely to have more difficulty in engaging with the new environment: Depressive symptoms (such as anxiety, withdrawal and loss of interest) can act as obstacles in the receptiveness of a resident in responding to social stimuli. Previous research on social engagement has been based on cross-sectional data, with a mixture of residents who had been in the nursing home for a variable period of time (Mor et al., 1995; Schroll et al. 1997, Resnick et al. 1997, Frijters et al. 2001). Little is known about the predictors, course and prevention of low social engagement. It is important to study the concept of low social engagement in newly admitted residents, because this can facilitate the development of preventative strategies.

We measured social engagement with the Index of Social Engagement (ISE), which is constructed with the 6 following (dichotomous) MDS-items: 1- at ease interacting with others, 2- at ease doing planned or structured activities, 3- at ease doing self-initiated activities, 4- establishes own goals, 5- pursues involvement in life of facility and 6- accepts invitations into most group activities (Mor et al. 1995). The ISE ranges from 0 (=lowest) to 6 (=highest level of social engagement). Depressive symptoms were measured with the MDS Depression Rating Scale (DRS): a 7-item scale, with all items to be scored 0 (indicator not exhibited), 1 (indicator of this type exhibited at least once in the last 30 days and up to 5 days a week) or 2 (indicator exhibited daily or almost daily) (Burrows et al. 2000). The scores range between 0 and 14. Two examples of the indicators are: *Sad, pained worried facial expression*; and; *persistent anger and irritabilities with self or others*.

51% of newly admitted residents had a low level of social engagement, and 27% were depressed (high levels of depressive symptoms). The items of the MDS-DRS showed good internal consistency (Cronbach's alpha = .87). Residents with low social engagement were significantly more often found to have many depressive symptoms (OR 3.3) Confounders did not influence the strength of this relationship. Low social engagement on admission was also associated with low cognitive performance and to a lesser extent by impairments in vision and ADL. The relationship of depressive symptoms and cognitive decline with social engagement was found to be stronger than the relationship between sensory or ADL-impairment and social engagement. Other research on social engagement found stronger relations with ADL and sensory impairments (Schroll et al. 1997, Resnick et al. 1997). The main difference with this study was that they did not control for depressive symptoms. These results stress the need for thorough

multidimensional assessment, including psychosocial needs, immediately on admission. An issue that was not studied or discussed was the role of nursing home staff in helping to establish social linkages. A significant proportion of nursing home residents have very few friends or 'engaged' family members. If staff could facilitate these linkages to other residents, staff, family, and others, this may have an important beneficial impact on the quality of life of those residents.

Research Question 6 (Chapter 7):

Is previous place of residence a predictor of depressive symptoms measured with the MDS-DRS?

The study on newly admitted resident functioning continues with a study on the impact of the previous place of residence. In studies that have been performed on the impact of nursing home admission, it is shown that patients are overwhelmed (Wilson 1997, Patterson 1995). It has not been investigated if the previous place of residence plays a role in this adjustment. The hypothesis was tested that being admitted form home is a more stressful life event (and therefore may lead to more depressive symptoms) compared to being admitted from another institutional setting (residential facility or hospital). There is a greater loss in several respects: A loss of autonomy and confidence but also a loss of possession and of one's own familiar environment. There has been little previous research on the impact of nursing home admission on the development of depressive symptoms (Patterson 1995, Lee et al. 2002; Pot et al., in press). There are studies on major depression in recently admitted nursing home residents: 42% of them continued to meet full criteria one month later, 27% achieved partial remission and 31% were in full remission (Raue et al. 2003).

Being admitted from home (compared with admission from an institutional setting) was an independent risk-indicator for depressive symptoms (OR 2.0). This result was controlled for social variables (social engagement and living with partner) and for health related variables (such as heart failure and chronic obstructive pulmonary disease).

The use of anxiolytic medication (OR 3.8), low social engagement (OR 2.7), and mild (OR 2.2) or moderate (OR 2.3) cognitive impairment were also strongly associated with depressive symptoms.

The results might be explained by the loss of autonomy and the loss of one's own environment, and the difficulties to adjust to the life in an institution (Patterson 1995). The stress of admission may be enhanced by the dramatic sequence of events which often precedes admission, like losing loved ones and emerging physical dependence. However, additional research is needed to unravel the impact of various factors before and shortly after transition to the nursing home, which include characteristics of the patient, the 'old' environment, social network, nursing home appearance and policy.

The study on newly admitted nursing home resident functioning continues with two studies on pain. Pain in the nursing home is known to be very prevalent and the management of pain not particularly good. Next to patient characteristics, facility characteristics may be important in the quality of assessment and management (Ferrell 1995, Frampton 2003). Therefore, the relation of pain is studied in chapter 8 with important and complex patient characteristics, and in chapter 9 with a facility characteristic.

Research Question 7 (Chapter 8):

Is pain prevalence different in the following three groups: cognitive intact patients, cognitive impaired patients with CRF and cognitive impaired patients without CRF?

It is important that clinicians appreciate the complex relations between dementia and pain, because pain is a treatable nuisance and a possible cause for behavioral disturbances (Geda & Rummans 1999). Alzheimer patients show a decreased pain experience (through an increased pain tolerance), whereas patients with vascular dementia are thought to have an increased pain experience, induced by white matter lesions (WML) in the brain (Scherder et al. 2003). Most nursing home residents with dementia have had no Magnetic Resonance Imaging (MRI) of the brain, which is the only way to show these WML, and therefore to discriminate between dementia with an decrease (Alzheimer) and an increase in pain experience (vascular dementia). Pain assessment and management in nursing homes could be improved if we used a measure (or proxy), simpler than MRI for evaluation WML. It was assumed that cardiovascular risk factors (CRF) could function as a proxy for these changes in neuropathology (Swieten van et al. 1991, Schmidt et al. 1995).

The results of this study show that in patients with cognitive impairment and CRF (probable vascular dementia), pain is more often observed than in patients with cognitive impairment without CRF (OR 2.08). Whereas all patients with cognitive impairment were observed to have less pain than those who are cognitively intact, this difference was found to be stronger for patients without CRF: OR was 0.59 for the cognitively impaired group with CRF (vascular dementia), and OR 0.28 for the cognitively impaired group without CRF (Alzheimer).

These findings support the hypothesis that whereas Alzheimer patients experience less pain than cognitively intact patients, vascular dementia patients with extensive white matter lesions (WML) experience more pain than Alzheimer patients (with no WML).

Research Question 8 (Chapter 9):

Does the type of special care unit influence pain assessment and management?

The issue of *pain management* in nursing homes has received little attention in research. Although there are specific problems in this population, such as sensitivity to side effects of drugs, the consensus is that good pain management is very well possible, but that pain management is often inadequate (Ferrel 1995). Pain management in dementia patients is perhaps even worse, because of communication and detection difficulties, and the fear of inducing side effects and polypharmacy (Frampton 2003). Earlier studies suggest that Alzheimer patients generally receive less pain medication. (Scherder et al. 1997)

More insight into factors that influence the assessment and management in dementia patients is necessary (Ferrel et al. 1995, Frampton 2003). One of these factors might be the environment.

In the Netherlands, residents with dementia are admitted on specialized psychogeriatric wards and residents with other diseases are often separated in long-term care, palliative or rehabilitation wards (Hoek et al. 2000). The specialized psychogeriatric wards are comparable to the Special Care Units (SCU) for Alzheimer disease in the USA. SCUs pay special attention to behavioral interventions while minimizing psychotropic medication and the use of restraints. It is unknown what the quality of pain assessment and pain management is compared to other wards with a more physically oriented care (Gerdner & Beck 2001, Kane et al. 1998, Warren et al. 2001, Lane et al. 2003).

The results of this chapter are that patients on psychogeriatric wards had less observed pain (OR 0.45) than patients on somatic wards, even when we controlled for possible confounders such as age, gender, cognitive status, ADL, pain related disorders and depression. Patients on psychogeriatric wards also received less pain medication (controlled for the intensity of pain): OR 0.37, compared to the somatic ward. We conclude that residing on a psychogeriatric care ward has a negative impact on the recognition and treatment of pain. A possible explanation may result from one of the strengths of specialized psychogeriatric wards: they are generally more likely to aspire to fewer medications (Kane et al. 1998). However, this may have a negative impact on the quality of pain management. The most important conclusion of this section is that there is little reason to doubt the reliability and validity of the data. There was a cross-sectional design, so the relations and associations found should not be mistaken for causality. With regard to the external validity of the results, it is important to stress that the results, until proven otherwise, only apply to newly admitted Dutch nursing home residents.

Theoretical and methodological reflections

The studies in part III of this thesis on patient functioning (chapter 6, 7, 8 and 9) are based on data of an observational study among newly admitted nursing home residents. The datacollection of the other chapters has been extensively discussed in other publications: Gerritsen 2004 (chapter 3) and Holtkamp 2003: (chapter 5)

Composition of the sample

The age and gender of the included residents (N=562) were comparable to all new nursing home admissions in the Netherlands (Arcares 1998). However, the sample consisted of more residents admitted on psychogeriatric wards than the 1998 national average (44% versus 33.6%), and less residents admitted from hospital (27.2% versus 49.7%). This difference suggests that the nursing home physicians in training had relatively more psychogeriatric patients and fewer rehabilitation patients in care. This however has not lead to serious under representation of certain groups of patients.

All included patients were newly admitted and assessed within 10 days of admission.

This is an advantage for the study into the relationship between patient and environmental characteristics, because all patients are expected to be approximately in the same phase of adjustment (Patterson 1995).

However, it is also a disadvantage: Care is required in attributing the findings to treatment or care provided at that moment, on a specific ward. Although there are good reasons to believe that patients are thoroughly assessed within a few days, and policies and treatment plans also are adjusted timely (especially in teaching nursing homes), this remains the largest uncertainty in the conclusions of part III of this thesis. Does the adjustment process of the newly admitted patient affect the data on the functioning of the patients? It is known that it takes about six months for the patient to fully adjust herself to the new institution (Patterson 1995). Hence, it is unknown whether the conclusions also hold for chronic nursing home populations. This needs further study. Until that, the found relations are only valid for newly admitted residents.

Data-collection by nursing home physicians in training

One might question the quality of the data collected by nursing home physicians in training, because observation of patient functioning is not a part of the regular training of physicians. Although the physicians in training collecting the data in this study received oral and written instructions for observation and scoring, they did not receive any further training. Furthermore, they varied in their motivation and did not chose to become an assessor, nor did they receive any payment for inclusion. They could choose from different strategies (all new patients, the first 5, or every 5th). Not surprisingly, the number of patients assessed varied considerably for each

individual nursing home physician in training. Nevertheless, the quality of the data is supported by the good internal consistencies for the different scales used in part III on patient functioning.

Data-collection in teaching nursing homes

Another question is whether the 65 teaching nursing homes in which the data were collected for this study are comparable to all nursing homes in the Netherlands. Teaching nursing homes have to fulfill requirements concerning quality and quantity of staff, procedures, care and patients. This probably has lead to the exclusion of smaller nursing homes, and nursing homes with major quality problems.

MDS-data in this study

The reliability of the MDS pain items showed large variability between facilities in the United States (Mor 2004). This is a problem when using MDS pain data which have been collected in facilities where the assessment process may be inadequate (Schnelle et al. 2001, Engle et al. 2001). In this study, great attention was paid to the assessment process and the assessors were well trained. Furthermore, the relations with another pain instrument (the Nottingham Pain Profile) and with pain medication was high, much higher than in other studies, (Cohen-Mansfield 2004, Fisher et al. 2002) and the internal consistency of the MDS-scales (social engagement and depressive symptoms) was high.

Cross-sectional design

The research in chapters 6, 7, 8 and 9 all measure health and functioning at one point in time. Such a cross-sectional design has two important limitations. First of all, conclusions on causality cannot be drawn. For instance, do depressive symptoms reduce social engagement, or does a low level of social engagement induce depressive symptoms? These relationships are rather complex, and often reciprocal.

In addition, important longitudinal aspects are not measured, that may influence cross-sectional associations: Holtkamp (2003) studied depression with the MDS, and found that residents who were recently deteriorated in ADL had significant more symptoms of depression measured with the MDS-DRS. Additional comprehensive longitudinal data-collection should control for recent change in patient functioning.

Dichotomous measures

All measures were categorized or dichotomized in the analysis of the data to create output that can be translated to every day clinical practice. Dichotomizing the data enables estimating effect-

sizes with confidence intervals. The simplification of functioning leads to a loss of information and statistical power.

The conclusion is that there is little reason to doubt the reliability and validity of the data of chapters 6-9. It was a cross-sectional design, so the relations and associations found should not be mistaken for causality. With regard to the external validity of the results, it is important to stress that the results, until proven otherwise, only apply to newly admitted Dutch nursing home residents.

The MDS in nursing home care

As we saw in chapter 2, comprehensive multi-domain assessment is very important for nursing home care planning because of the complex and often interrelated problems on many domains in health and functioning. There is no multi-domain instrument that has been tested so profoundly for reliability, validity and effects of implementation as the MDS-RAI (Holtkamp 2003). Overall, reliability and validity for care planning ranged from adequate to excellent and implementation has lead to improvements in quality of care, and (although to a lesser extend) in quality of life and health.

However, considering the comprehensiveness and refinement of the MDS-RAI, one can argue that the moderate effects of implementation on patient outcomes that have been found are disappointing. Why are these effects moderate, not measurable or not present?

The MDS has been found to improve the quality of care in the USA, Sweden, Japan and the Netherlands, but the effects were moderate on other outcomes, such as health, functioning and quality of life (chapter 4, chapter 5, Holtkamp 2003). According to the quality of care dimensions by Donabedian (1985), a change in structure of care will lead to a change in process and consequently to a change in outcome (Donabedian 1985, Holtkamp et al. 2000). The implementation of the MDS-RAI is a structural dimension of quality of care, which influences the process of care. This change will influence resident outcomes like physical health and perceived quality of life.

Changes in the care process have been found: Better case history, better care plans.In addition, Holtkamp et al. (2001) found that implementation of the MDS-RAI has led to statistically significant less unmet needs: In other words, the needs as formulated by the residents were better met by the nurse or other care givers. However, this effect was not very strong, just as the improvements described in chapter 5 are not very strong.

Previous research on other types of broad implementation also found small or unconvincing improvements compared to the expected impact: the implementation of emotion-oriented care

(Finnema et al. 2001, Schrijnemaekers et al. 2003), resident oriented care (Berkhout 2000, Berkhout et al. 2004) differentiated practice (Jansen et al. 1997) and communication training for nurses of cancer patients (Kruijver et al. 2001)

The limited effects found may be partly explained by suboptimal compliance in a multicentre implementation study (Schrijnemaekers et al. 2002).

Another explanation for the moderate effects that are frequently found in research on extensive and complex (but high potential and promising) implementations can be sought in the distinction between *competence* and *performance*. Competence comprises of knowledge, skills and attitudes and is usually considered as an important mediator in performance in daily practice, and is widely used for teaching and assessment targets. (Francke et al. 1995, Holtkamp 2003). Performance relates to the actual demonstration of skill in day-to-day practice. In the Dutch study on the implementation of the MDS-RAI (chapter 5) the shortage of qualified staff and difficulties with the computerization were obstacles in completing the assessment process, and thus in the actual performance. Despite the improvement of the competence of the nurse assessors because of the training in the MDS-RAI, the performance (the assessment) hardly changed. (Holtkamp 2003).

Another explanation why more robust patient outcomes have not been found might be sought in the difficulty of relating interventions to distant outcomes: i.e. which requires a longer chain of effects For example structural changes in the nursing home affects the care-process, and this leads to effects on health, and these to effects on quality of life. A study on the effects of the implementation of the Eden Alternative (a systematic introduction of pets, plants, and children) in a nursing home found no beneficial effects on cognition, functional status, survival, infection rate, or cost of care after 1 year. However, qualitative observations at the Eden site indicated that the change was positive for many staff as well as residents (Coleman et al. 2002). This suggests that it may take longer than a year to demonstrate improvements attributable to promising, complex and extensive intervention. (Coleman et al. 2002)

The use of MDS data for research

The debate whether MDS data should be used for research started just after the introduction of the MDS (Teresi & Holmes 1992, Hawes et al. 1992). One of the key elements in this discussion is the accuracy and reliability of the data, when the assessments are not conducted by research staff (Teresi & Holmes 1992). Reasons for this variability are:

-the approach of the facility (who is conducting the assessment? Who participates in the assessment? How much time is put into the assessment?),

-the sources of information (is the MDS item turned into a question to the resident or family member? How many sources of information are used?)

These are potential sources of variability in measurement accuracy, but field-testing has found no such *overall* problems in reliability when regular staff assessments were compared to research staff assessments (Hawes et al. 1995, Sgadari et al. 1997, Morris et al. 1997). Substantial inter-facility variability however has been demonstrated, with a minority of facilities performing poorly (Mor et al. 2003).

An advantage of having comprehensive and population based data on a large number (or all, in the USA) of the nursing home residents is that it facilitates observational and evaluative research, on quality of care and the functioning of patients with multidimensional complex problems (Mor 2004). The number of studies that have been performed with the MDS is enormous, on specific diseases like Parkinson and Multiple sclerosis (Buchanan et al. 2002, Buchanan et al. 2003), on specific conditions like incontinence and constipation (Bean et al. 2003, Robson et al. 2000), on matters related to care processes like tube feeding (Mitchel et al. 2003) and restraint use, and on medication use (Won et al. 2004). The MDS has proven to be a valuable source of information on nursing home residents' functioning for research purposes. However, ongoing considerations about the reliabilty and validity of the data should be present in all research, research with MDS-data is no exception on this rule.

Implications and recommendations

Comprehensive multidisciplinary assessment

Nursing homes provide care and a customized living environment for frail residents. This should include, in addition to adequate treatment and personal care, facilitating psychosocial well-being and social interaction. Thorough assessment of these needs, immediately after admission and on a regular basis, is imperative (Hertogh et al. 1996). The MDS-RAI is an useful instrument for these purposes. It can help to ensure that problems of the resident are not overlooked. This is especially important in the present nursing home care in the Netherlands, where financial cut-backs put pressure on the multidisciplinary way of working. However, the strength of the MDS-RAI in performing a broad, comprehensive assessment can never replace different professions in the nursing home: It does not replace a therapist, physician or psychologist, but its strength is that it brings information on different domains together in a comprehensible manner. It facilitates screening and communication between caregivers. It also provides an additional common framework and language for the care plan.Therefore, implementation of the MDS-RAI in nursing home care is recommended.

Improvement of implementation of the Minimum Data Set (MDS) in Dutch nursing homes

The MDS has been found to improve the quality of care in the USA, Sweden, Japan and the Netherlands. However, the results in chapter 5 showed that the implementation of the MDS-RAI is more difficult that the participating nursing homes had anticipated. It is remarkable that although there are thousands of institutions in several countries implementing the MDS-RAI, there is no study on the pitfalls of implementation. The literature on MDS-RAI implementation has been superficial so far (Bernabei et al. 1997, Blair et al. 1999, Brunton & Rook 1999., Ossip-Klein et al. 2000). The implementation of an instrument like the MDS-RAI influences both the structure and process of care, and is therefore more complicated than other quality improvement implementations that have a more defined focus (for example pressure ulcers). The implementation of the MDS in the USA was mandatory, and MDS forms had to be filled out one way or another, sometimes with the help of an 'assessment nurse'. This may result in *unreliable* data in research and residents that will not profit from the assessment.

In the Netherlands, where the implementation of the MDS is on a voluntary basis, this may result in *absent* data. The implementation process in countries where the MDS is mandatory compared to where it is voluntary, deserves more attention.

The MDS has an embedded link to Resident Assessment Protocols (RAPs), which are akin to clinical treatment guidelines. They have been designed to help caregivers to analyze clinical problems, which are prevalent and important in nursing home care. Personal communications with nursing home workers in the United States and the interviews in Dutch nursing homes in

chapter 5 suggest however that the RAPs of the RAI are infrequently and inadequately used both in the United States and in the Netherlands. Although there are 18 RAPs, only a few have been validated or studied. It has been established that the RAP 'pressure ulcer' is valid: It identifies patients at risk of pressure ulcer development (Brandeis et al. 1995). The validity of the RAP 'incontinence' has shown variable results (Crooks et al. 1995, Resnick et al. 1996, Brandeis et al.1997). The RAPs generally received the least attention in research, and it is not known whether they are used as a clinical tool.

Many more applications of the MDS-RAI are available when the MDS has been computerized. But availability does not mean that they are used: Transferring resident information, using summaries as a means of enhancing clinical information are a few examples, which are available in most nursing homes in the USA, but they are infrequently used (Ossip-Klein et al. 2000).

Improvement of the MDS-RAI

Pain

Pain assessment and management is a challenge in nursing home care, especially in cognitively impaired residents. The introduction of a RAP for pain and an additional pain item in the MDS, for instance with drawings of facial expressions might improve the reliability and validity of pain assessment with the MDS for cognitively impaired patients (Frampton 2003, Kamel et al. 2001). However, more research on applicability, reliability and validity of this additional pain measurement is necessary.

Depression

The RAP *mood state* is triggered when at least one of 12 mood items (the 7 that are included in the MDS-DRS and 5 others) is positive. This seems to provide too little specific information: 68% of the residents in our sample scored positive on at least one of the 7 mood items. Such a sensitive trigger is likely to be ignored in the busy nursing home practice. Screening and adequate staff reaction could be improved by using a more specific measure, like a DRS score of 3 or higher.

The American Geriatric Society and American Association for Geriatric Psychiatry has recommended that besides the MDS, other depression screening instruments should be conducted, routinely 2-4 weeks after admission and thereafter every 6 months(American Geriatrics Society and American Association for Geriatric Psychiatry 2003). This advise was based on one study with questionable reliability, in which the MDS-DRS performed poorly (Anderson et al. 2003). If data are not collected on a reliable manner (for instance if facilities only see the MDS as an administrative obligation) the validity will also be limited. If routine data collection in daily practice might be unreliable because of the administrative burden, this is likely to occur with other routinely used screening instruments.

Reliability MDS

It is a revolutionary situation for (nursing home) research that there are millions of data sets on so many aspects of functioning, on a longitudinal basis. The biggest methodological concern with such a *quantity* of data still lies in the *quality* of the data, just as it did in the beginning of the MDS (Teresi & Holmes 1992). Therefore, the best investment for nursing home research would be to investigate the inter-facility variation of the reliability. Insight into the assessment process, as well as into the reasons behind choices which facilities make in this process, may illuminate the background of this variation. In addition, such insight may suggest procedures for selection and exclusion of facilities that perform poorly, when using MDS data for research purposes.

Patient functioning: depressive symptoms and pain

Newly admitted residents have many depressive symptoms, especially those who are admitted from home. It is known that depression has an impact on well being and the use of services (Beekman et al. 2002). A recent study showed that the start of long-term care (including nursing home placement) and the enduring use of long-term care may also increase depressive symptoms (Pot et al., in press). Therefore, there should be more research into the course of depression prior to and just after nursing home admission to shed light on the relationship between depressive symptoms and the use of nursing home care.

Although there are no interventions studied, it is likely that individual attention or structured group meetings for newly admitted residents could ease the burden of these symptoms. Attention should be paid to the difficulties in adjusting to the new environment, making new social ties, adjusting to functional limitations and how to establish a satisfactory sense of autonomy within the limitations of the facility. The nursing home needs to be constantly aware of the dangers of procedures and rules that may turn it into a 'total institution' (Goffman 1963, Morley & Flaherty 2002) The negative effects of admission to an institution, and the ways these effects can be prevented deserve more attention in both nursing home practice and research. The Dutch society for nursing home physicians (NVVA) should take the initiative for making a multidisciplinary guideline for depression, to improve the recognition and management of depression by nursing home physicians (Falck et al. 1999). Also, broader implementation of guidelines that already have been developed, for instance for nurses could improve the care for depressed nursing home patients (Verkaik et al. 2003)

In this thesis, several aspects have been discarded: for example personal coping resources and social support. Especially because these were newly admitted nursing home residents, these factors could have influenced depression, social engagement and pain. It has been established that coping resources and social suport can have a protective (buffering) effect on depressive symptoms for some chronic diseases (Bisschop et al. 2004). This is a limitation of this study. Care planning and research could benefit from the introduction of items in the MDS that cover social support and coping resources (see also: Gerritsen 2004). The results of the research on pain in this thesis confirm other international research: Pain assessment and management in

nursing homes is inadequate (Ferrell 1995, Frampton 2003). This prompts for further research into possibilities of multidimensional programs for improving pain assessment and management, such as the one that was performed by Jordan-March et al (2004). An essential part of that program was a national guideline. The Dutch association of nursing home physicians (NVVA) could provide a large contribution to the improvement of pain assessment and management by ordering a guideline for pain in the nursing home.

This thesis has shown that the MDS-RAI is a valuable instrument for research on the quality of care and patients' functioning in nursing homes. The MDS-RAI enables important research to improve the quality of care and patients' functioning. Therefore, residents, caregivers and researchers may benefit from assessment with the MDS.

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Samenvatting

Zorgen voor kwaliteit: Het gebruik van de Minimum Data Set (MDS) voor onderzoek naar kwaliteit van zorg en het functioneren van patiënten in verpleeghuizen.

Introductie

Ik werk in het verpleeghuis als verpleeghuisarts. Daar behandel en verzorg ik, samen met veel toegewijde collega's van allerlei opleiding en achtergrond, mijn patiënten. Deze patiënten zijn over het algemeen lichamelijk en/of geestelijk kwetsbare ouderen. De noden en aandachtspunten liggen op zo veel terreinen, en zijn vaak zo complex met elkaar verweven dat een grondige beoordeling van deze terreinen noodzakelijk is om goede zorg te kunnen verlenen. In Nederland is nog niet veel onderzoek gedaan naar instrumenten die deze grondige en brede beoordeling kunnen uitvoeren, en internationaal is er slechts één instrument goed onderzocht: de Minimum Data Set van het Resident Assessment Instrument (MDS-RAI). Dit proefschrift handelt over het functioneren van verpleeghuispatiënten en het gebruik van de MDS-RAI voor onderzoek daarnaar.

Probleembeschrijving

Het verpleeghuis is niet meer het 'oude mannen en vrouwen huis' van de middeleeuwen, of het 'ziekenhuis voor chronisch zieken' van het begin van de twintigste eeuw. Verblijf en verpleging waren daar vrijwel het enige dat geboden werd. In de loop van de jaren is de behandelfunctie van het verpleeghuis fors uitgebreid, wat onder andere heeft geresulteerd in een toename van de revalidatiefunctie en dagbehandeling. Tegenwoordig zijn er meer dan 300 verpleeghuizen waar 55.000 patiënten (gemiddelde leeftijd boven de 80) verblijven, verzorgd en behandeld worden.

In het verpleeghuis wordt een breed scala aan zorg geleverd, waaronder chronische zorg aan patiënten met allerlei somatische beperkingen (zoals mobiliteitsstoornissen), chronische zorg voor patiënten met een dementieel syndroom, zorg gericht op ontslag naar huis (revalidatie) na bijvoorbeeld een heupfractuur of beroerte en terminale zorg. Deze verschillende groepen worden meestal op aparte afdelingen opgenomen: zo zijn er somatische afdelingen, psychogeriatrische afdelingen en revalidatieafdelingen.

De meeste ouderen, ook die met een chronische ziekte, blijven in hun eigen woonomgeving en komen niet in een verpleeghuis. Diegenen die uiteindelijk worden opgenomen hebben vrijwel altijd een complexe zorgvraag. Zij hebben vaak meerdere (chronische) ziekten en ernstige functionele beperkingen. Problemen kunnen zich voordoen op diverse gebieden zoals mobiliteit, dagelijkse bezigheden (zoals wassen, eten en kleden), communicatie, stemming, rouwverwerking, cognitie en psychosociaal en lichamelijk functioneren (denk aan pijn en benauwdheid).

Het is van belang dat de complexe zorgvraag van een verpleeghuispatiënt gestructureerd en regelmatig in kaart gebracht wordt om adequate zorg te kunnen leveren. Dit is de enige manier om discrepanties tussen de noodzakelijke en de daadwerkelijk geboden zorg te voorkomen.

Naast het inventariseren van actuele problemen is het voor deze kwetsbare groep ouderen van groot belang dat frequent voorkomende aandoeningen zoals depressie en decubitus in een vroeg stadium worden herkend. Of nog beter: om al in actie te komen als de aandoening nog niet is

opgetreden, maar wel een verhoogd risico aanwezig is, zodat met gerichte preventieve maatregelen getracht kan worden de aandoening te voorkomen.
Er zijn verschillende instrumenten ontwikkeld om problemen van verpleeghuispatiënten te inventariseren om hiermee de kwaliteit van zorg in het verpleeghuis te kunnen verbeteren. In de literatuur worden elf van deze multidimensionele instrumenten beschreven. Hoewel het gebruik van al deze instrumenten waarschijnlijk zal bijdragen aan betere zorg, is er maar één instrument uitvoerig wetenschappelijk onderzocht wat betreft betrouwbaarheid, validiteit en effecten op kwaliteit van zorg, gezondheid en kwaliteit van leven, namelijk de Minimum Data Set (MDS) van het Resident Assessment Instrument (RAI).

Hoofdstuk 2 van dit proefschrift beschrijft de MDS-RAI, en haar psychometrische eigenschappen. Het RAI is rond 1990 ontwikkeld in de Verenigde Staten, als antwoord op zorgen over de kwaliteit van zorg in verpleeghuizen vanuit de Amerikaanse samenleving. Naast een grote hoeveelheid incidenten die in de media breed werden uitgemeten, waren er ook cijfers waaruit bleek dat de kwaliteit van zorg beter kon; zo was het gebruik van kalmerende geneesmiddelen te hoog en werden vrijheidsbeperkende middelen (zoals Zweedse banden) te gemakkelijk toegepast. Er werden ook (te) veel patiënten tussentijds opgenomen in het ziekenhuis. Om de kwaliteit van zorg in verpleeghuizen te vergroten, heeft het Amerikaanse congres besloten opdracht te geven tot het ontwikkelen van het RAI.
Het RAI bestaat uit een lijst met vragen, de Minimum Data Set (MDS), die door hulpverleners bij opname en daarna iedere drie maanden moet worden ingevuld. Het betreft vragen die door middel van observaties, (hetero-)anamnese en gesprekken met andere hulpverleners kunnen worden ingevuld. De MDS omvat de domeinen die voor de zorg aan een verpleeghuispatiënt belangrijk zijn (zie tabel 1).

Tabel 1: Inhoud Minimum Data Set en Resident Assessment Protocollen (MDS-RAI 2.0)

Minimum Data Set- onderdelen	Resident Assessment Protocollen
Persoonsgegevens	Delier
gewoonten & routines	Cognitief verval/dementie
identificatie- en achtergrondinformatie	Gezichtsvermogen
cognitief functioneren	Communicatie
communicatiepatronen/gehoor	ADL en mogelijkheden voor revalidatie
gezichtsvermogen	Urine-incontinentie en verblijfskatheter
stemmings- en gedragspatronen	Psychosociaal welbevinden
psychosociaal welbevinden	Stemming
lichamelijk functioneren en structurele problemen	Problematisch gedrag
(waaronder ADL en mobiliteit)	Activiteiten
continentie in de laatste 14 dagen	Valpartijen
diagnosen van ziekten	Voedingstoestand
gezondheidsproblemen	Voedingssondes
toestand van mond/voeding	Uitdroging/vochtbalans
toestand van mond/gebit	Zorg voor het gebit
conditie van de huid	Decubitus
activiteiten verrichtingen patroon	Psychofarmacagebruik
medicijngebruik	Lichaamsfixatie
speciale behandelingen en procedures	
ontslagmogelijkheid en algehele toestand	
informatie over de beoordeling	

Daarnaast bevat het RAI rekenregels waarmee scores op vragen uit de MDS worden omgezet in signaleringen van achttien probleemgebieden. Zo wordt het probleemgebied decubitus gesignaleerd wanneer er sprake is van: verminderde beweeglijkheid in bed, bedlegerigheid, incontinentie voor faeces, een perifere vaataandoening, fixatie, ongevoeligheid van de huid of de aanwezigheid van een zweer. Deze probleemgebieden zijn door een panel van deskundigen uit onderzoek en verpleeghuispraktijk samengesteld en representeren de belangrijkste en meest voorkomende aandachtsgebieden voor verpleeghuispatiënten. Voor deze achttien probleemgebieden zijn in de VS richtlijnen ontwikkeld die de hulpverleners kunnen raadplegen. Deze richtlijnen worden Resident Assessment Protocollen (RAP's) genoemd, en zijn primair bedoeld om de hulpverleners te begeleiden bij het opstellen van een adequaat zorgplan. (zie ook tabel 1 en Box 1) De ontwikkeling en implementatie van het RAI in de Verenigde Staten is een enorme inspanning geweest waarmee men niet alleen de patiëntgebonden zorg, maar ook de zorg op afdelings- en verpleeghuisniveau heeft trachten te verbeteren. Daarom zijn in de MDS ook meerdere items ten aanzien van dezelfde probleemgebieden opgenomen. Deze maken het

mogelijk het functioneren van patiënten te meten door middel van schalen, voor bijvoorbeeld depressieve symptomen, benodigde hulp bij ADL, cognitief functioneren en sociale betrokkenheid.
De gegevens die met het MDS-RAI worden verzameld zijn over het algemeen voldoende betrouwbaar en valide voor het maken van een zorgplan en het doen van onderzoek. Met name het onderzoek naar lichamelijk en cognitief functioneren laat uitstekende resultaten zien. Gedrag en stemmingsschalen binnen de MDS zijn over het algemeen wat minder, maar wel voldoende goed. Een belangrijk aandachtspunt is de grote variatie in de betrouwbaarheid tussen verpleeghuizen in de Verenigde Staten. Het verzamelen van MDS-RAI gegevens is daar verplicht, maar deze variatie zou er op kunnen wijzen dat er verpleeghuizen zijn die hier 'met de pet naar gooien'.

Veel verpleeghuispatiënten vertonen gedrag, dat henzelf en anderen in problemen kan brengen: er wordt dan ook wel gesproken over gedragsproblemen of probleemgedrag. Een van de belangrijkste problemen hierbij is dat dit gedrag irritatie, frustratie en/of afwijzing kan veroorzaken bij professionals, andere bewoners en bezoekers. Hierdoor kan de bereidheid om de behoeften van de patiënt te vervullen in gevaar komen, wat haar welbevinden zal schaden. Gedrag wordt dan gezien als een signaal, niet als een probleem. Dit heeft ons geïnspireerd om in **hoofdstuk 3** een schaal te ontwikkelen met MDS-items, het *Prikkelend Gedrag Profiel* (Challenging Behavior Profile CBP). Allereerst zijn de relevante items geselecteerd door vijf klinische experts. Vervolgens is met een gegevensbestand van 656 verpleeghuisbewoners door middel van statistische analyses een betrouwbare en valide schaal ontwikkeld. De schaal bestaat uit 4 domeinen of subschalen: *conflict gedrag, teruggetrokken gedrag, steunzoekend gedrag en rusteloos/repetitief gedrag*. Aanvullende analyses op 227 andere verpleeghuispatiënten lieten voldoende, maar wel minder goede, resultaten zien. Deze gedragschaal lijkt een belangrijke, veelbelovende aanvulling op de al bestaande MDS-RAI schalen.
In **hoofdstuk 4**, wordt de internationale literatuur over de effecten van implementatie van het MDS-RAI besproken. Invoering van MDS-RAI heeft zowel in de Verenigde Staten, als in Japan en Zweden geleid tot betere kwaliteit van zorg: betere, nauwkeuriger en completere zorgplannen en zorgdossiers, en het beter 'vinden' van belangrijke problemen. Bij geen van deze studies was echter sprake van een vergelijking met verpleeghuizen die MDS-RAI niet hadden geïmplementeerd. Op het gebied van de gezondheid werden kleine veranderingen gevonden, vooral het aantal ziekenhuisopnames daalde, en sommige problemen zoals 'open benen' en uitdroging kwamen na invoering van het RAI minder vaak voor. De conclusie van dit hoofdstuk is, dat implementatie van de MDS-RAI in meerdere landen de kwaliteit van zorg lijkt te hebben verbeterd en dat de kwaliteit van leven en de gezondheid enigszins lijkt te zijn verbeterd na invoering van MDS-RAI. Omdat het hier echter geen van allen 'gecontroleerde' studies betrof, is het niet vastgesteld dat deze verbeteringen met zekerheid aan de invoering van MDS-RAI toe te schrijven zijn.

Hoofdstuk 5 beschrijft een gecontroleerd interventieonderzoek dat in Nederlandse verpleeghuizen is uitgevoerd naar de effecten van implementatie van het MDS-RAI op de kwaliteit van zorg. De kwaliteit van de coördinatie van verpleegkundige zorg is in dit hoofdstuk het object van studie. In totaal participeerden 348 patiënten op 16 verpleeghuisafdelingen. De helft van deze afdelingen implementeerden het MDS-RAI, de andere helft diende als controlegroep. Negen maanden na de voormeting scoorden de afdelingen die het MDS-RAI hadden geïmplementeerd beter op alle kwaliteit van zorg aspecten (zoals bijvoorbeeld kwaliteit van *zorgplan* en de *verpleegkundige overdracht*). Alleen de kwaliteit van de *verpleegkundige anamnese* was ook statistisch significant beter. Bij interviews met de leidinggevenden van de afdelingen bleek dat de meeste afdelingen, door ziekte, personeelsgebrek en automatiserings-perikelen niet in staat waren geweest het MDS-RAI te implementeren zoals men te voren had gepland.

Het MDS-RAI is behalve een instrument voor individuele zorgverlening ook te gebruiken om gegevens over het functioneren van verpleeghuispatiënten voor onderzoeksdoeleinden te verzamelen. Onderzoek kan helpen om verbanden te leggen, die behulpzaam kunnen zijn om betere zorg te leveren. Hoofstukken 6 t/m 9 maken gebruik van de gegevens van 562 patiënten die nieuw in het verpleeghuis waren opgenomen. Verpleeghuisartsen in opleiding observeerden de patiënten in 65 verpleeghuizen en vulden meerdere vragenlijsten in over het functioneren, en deze waren bijna allemaal afkomstig uit het MDS-RAI.

Hoofdstuk 6 handelt over de relatie tussen depressie en sociale betrokkenheid. Sociale betrokkenheid kan gezien worden als de mate waarin een patiënt initiatief en betrokkenheid toont voor de nieuwe omgeving (het verpleeghuis). Meer dan de helft van nieuw opgenomen verpleeghuispatiënten heeft een lage sociale betrokkenheid, en ruim een kwart heeft veel depressieve symptomen. De resultaten uit dit hoofdstuk suggereren dat stemmingsproblemen een goede sociale betrokkenheid bemoeilijkt, meer zelfs dan dat lichamelijke problemen dat doen. Cognitieve stoornissen, problemen met zien en afhankelijkheid bij de ADL hebben ook een relatie met meer depressieve symptomen.

De opname in het verpleeghuis is een belangrijk moment: de patiënt is kwetsbaar vanwege lichamelijke en/of cognitieve beperkingen, en dan verdwijnt ook nog haar vertrouwde omgeving, haar bezittingen, en gelden de regels van het verpleeghuis, en niet van haar eigen huis. Deze verliezen maken iemand mogelijk gevoelig voor het ontwikkelen van stemmingsstoornissen. Bij pas opgenomen verpleeghuispatiënten maakt het wellicht uit of zij opgenomen zijn vanuit hun eigen huis, of vanuit een andere instelling (bijvoorbeeld het ziekenhuis). De gedachte hierachter is, dat het verlies groter is bij een patiënt die vanuit haar eigen huis wordt opgenomen. Dit is nog niet eerder in onderzoek aangetoond, daarom is dit in **hoofdstuk 7** van dit proefschrift onderzocht. Uit de resultaten blijkt dat zij die vanuit hun eigen huis worden opgenomen veel vaker (veel) depressieve symptomen hebben dan zij die vanuit een andere instelling of ziekenhuis worden opgenomen, zelfs als er rekening gehouden wordt met mogelijke verstorende (somatische en psychosociale) factoren.

Het proefschrift gaat verder met twee hoofdstukken over *pijn*. Het goed onderkennen van pijn in het verpleeghuis is niet makkelijk, onder andere door het veelvuldig voorkomen van communicatieve en cognitieve stoornissen. Pijn wordt anders beleefd door patiënten met Alzheimer-dementie dan door patiënten met een vasculaire dementie. Dit komt doordat de schade in de hersenen bij beide de pijnbeleving verandert: bij Alzheimer zou dit leiden tot een hogere pijndrempel, terwijl bij vasculaire dementie de schade juist voor meer pijnbeleving zou zorgdragen. Deze laatste schade ('witte stof' afwijkingen) zijn alleen met een speciaal onderzoek (een MRI-scan) zichtbaar te maken. De meeste verpleeghuispatiënten hebben echter nooit een MRI gehad, en zullen dat ook niet krijgen vanwege de kosten voor de samenleving en belasting voor de patiënt. **Hoofdstuk 8** gaat daarom op zoek naar een manier om toch meer te weten te komen over de aanwezigheid van deze witte stof afwijkingen. Omdat het bekend is dat er een relatie is tussen cardiovasculaire risicofactoren (=factoren die een grotere kans geven op hart en vaatziekten zoals hypertensie en diabetes) en witte stof afwijkingen, hebben wij de patiënten in 3 groepen ingedeeld. Een groep die geen cognitieve stoornissen had, een groep die cognitieve stoornissen had maar geen cardiovasculaire risicofactoren ('waarschijnlijke Alzheimers') en een groep met cognitieve stoornissen en ook cardiovasculaire risicofactoren ('waarschijnlijke Vasculaire dementie'). De 'waarschijnlijke vasculaire dementie' groep had duidelijk vaker pijn dan de 'waarschijnlijke Alzheimer' groep, al hadden beide groepen minder vaak pijn dan de groep die cognitief intact was. De hypothese werd hiermee bevestigd dat de aanwezigheid van cardiovasculaire risicofactoren een aanwijzing kunnen zijn dat patiënten met cognitieve problemen meer pijn hebben.

Pijn komt veel voor in het verpleeghuis, en veel wijst erop dat niet alleen het herkennen, maar ook de behandeling beter kan en moet. **Hoofdstuk 9** behandelt de vraag of het herkennen en behandelen van pijn in de Nederlandse verpleeghuissetting beïnvloed wordt door het type afdeling. De hypothese was, dat revalidatie- en somatische afdelingen meer gericht zijn op lichamelijk lijden dan psychogeriatrische afdelingen, en dat dit zowel de herkenning als de

behandeling beïnvloedt. Het onderzoek dat in dit hoofdstuk beschreven wordt laat zien dat er minder pijn wordt gevonden op deze psychogeriatrische afdelingen, zelfs als wordt gecontroleerd voor de aanwezigheid van cognitieve stoornissen en van somatische problemen, zoals de aanwezigheid van aandoeningen die met meer pijn gepaard gaan. Ook de behandeling was, ongeacht de hoeveelheid pijn, op psychogeriatrische afdelingen slechter. Er werden minder pijnstillers voorgeschreven, ook aan de patiënten die wel pijn hadden. De focus van artsen en verzorging op psychogeriatrische afdelingen is wellicht te weinig op pijn gericht. Dit is zorgelijk, omdat pijn ook gedragsproblemen kan beïnvloeden en zelfs veroorzaken. De aanwezigheid van pijn kan daarbij een belangrijke negatieve invloed hebben op de kwaliteit van leven.

Hoofdstuk 10 is een samenvatting en nabeschouwing van de vorige hoofdstukken. Er wordt kritisch aandacht besteed aan een aantal zaken die de resultaten hebben kunnen beïnvloeden.

De MDS-RAI is een voldoende betrouwbaar en valide instrument om goede individuele verpleeghuiszorg te faciliteren. De positieve effecten op de kwaliteit van zorg zijn in verschillende landen aangetoond, met verschillende instrumenten. De grootte van de effecten is echter kleiner dan te voren was verwacht. Ook zijn er positieve effecten gevonden op gezondheid en kwaliteit van leven, maar deze zijn niet overweldigend groot. Dit zegt overigens niet alleen iets over de MDS-RAI: in deze beschouwing worden een aantal andere 'brede' interventies in verpleeghuizen beschreven (onder andere belevingsgerichte zorg), die een geringer resultaat lieten zien dan tevoren verwacht. Mogelijk speelt hierbij een rol, dat sommige uitkomstmaten te ver weg liggen: van een betere verpleegkundige anamnese tot een gelukkiger patiënt is het nog een wereldreis. Daarnaast worden veel verbetertrajecten (zo ook de implementatie van het RAI) gefrustreerd door de beperkte middelen van het verpleeghuis. Ook wordt besproken dat het onderwijzen van een betere patiëntbeoordeling nog niet direct betekent dat de 'leerling' dit ook daadwerkelijk kan én doet.

Dit proefschrift laat ook zien dat met de gegevens die verzameld zijn met de MDS-RAI goed wetenschappelijk onderzoek gedaan wordt en kan worden. Wel wordt er speciale aandacht gevraagd voor het probleem van instellingen die de betrouwbaarheid van dataverzameling frustreren: instellingen die de MDS laten invullen door mensen die zich niet of in zeer geringe mate op de hoogte hebben gesteld van het functioneren van de patiënt. Dit zorgt voor potentiële verschillen binnen gegroepeerde databanken.

De samenstelling van de onderzoeksgroep (van hoofdstuk 6-9) was niet geheel representatief voor alle nieuw opgenomen Nederlandse verpleeghuispatiënten. Er waren minder patiënten die van uit hun eigen huis werden opgenomen, en er waren er minder die op de revalidatie werden opgenomen. Een ander aspect dat de resultaten heeft kunnen beïnvloeden, is de status van de patiënten: recent opgenomen betekent dat allerlei factoren vanuit de thuissituatie kunnen meespelen bij het functioneren van deze patiënten, in het bijzonder waar het de stemming en het gedrag betreft. Daarnaast was de onderzoekspopulatie wel heel erg heterogeen: somatiek, psychogeriatrie en revalidatie. Een groot deel van deze groep gaat weer naar huis, een andere grote groep blijft in het verpleeghuis voor de rest van hun leven. Dit

andere perspectief heeft zeker ook een effect op het psychosociale functioneren. Het is belangrijk dat voor de verschillende groepen verpleeghuispatiënten verder longitudinaal onderzoek plaatsvindt dat al begint wanneer de indicatie voor verpleeghuisopname wordt afgegeven.

Zowel het aantal als het percentage van ouderen met chronische ziekten zal de komende jaren fors stijgen. Investeringen in de zorg en het wetenschappelijk onderzoek zijn belangrijk om kwalitatief goede zorg te geven. Dit proefschrift is een stimulus voor verpleeghuizen om de MDS-RAI in te voeren als instrument om de zorgvraag te beantwoorden, en de kwaliteit te verhogen. Verder benadrukt het de noodzaak tot verder wetenschappelijk onderzoek op een structurele basis: groepen verpleeghuispatiënten dienen longitudinaal regelmatig beoordeeld te worden om meer inzicht te krijgen in de complexe relaties tussen lichamelijk en psychosociaal functioneren. De MDS van het RAI is ook hiervoor een goed uitgangspunt.

Box 1: Casus Mevrouw F

Mevrouw F, 75 jaar, verblijft sinds 8 jaar in verpleeghuis R. in verband met ADL-afhankelijkheid na een CVA.
Na het invullen van de MDS worden de volgende probleemgebieden gesignaleerd:

1- ***Urine-incontinentie/verblijfskatheter***
·Gesignaleerd vanwege aangekruist MDS-item:
·**Gebruik van incontinentie materiaal**

2 -*Decubitus*
·Gesignaleerd vanwege:
·**Incontinentie van de darmen**

3- Activiteiten
Gesignaleerd vanwege:
·**Bijna altijd wakker in de ochtend**
·**Niet betrokken zijn bij activiteiten**
4- Psychosociaal welbevinden
Gesignaleerd vanwege:
·**Stelt zich eigen doelen**
·**Bedroefd over verloren rollen/status**
·**Dagelijkse routine verschilt erg van thuis**

5- ***Cognitief verval/dementie***
Gesignaleerd vanwege:
·**Probleem met korte-termijn geheugen**
·**Probleem met lange-termijn geheugen**
·**Probleem met nemen beslissingen (verminderd zelfstandig)**

In het multidisciplinaire overleg (MDO) wordt de toestand van mevrouw aan de hand van deze *signaleringen*, en de bijbehorende RAP's besproken:

Ad 1: De incontinentie is al jaren bekend, en uitgebreid onderzocht. De aanbevelingen voor onderzoek naar de oorzaak van incontinentie zoals die in het RAP voor Incontinentie staan, hoeven dus nu niet opgevolgd te worden. Gebruik van incontinentiemateriaal is verder naar tevredenheid en er is dus geen sprake van een actief probleem.

Ad 2: Mevrouw heeft een verhoogde kans op decubitus, wat niet eerder herkend is. Besloten wordt tot een preventieve antidecubitus-matras, en een aangepast kussen in de rolstoel.

Ad 3: Mevrouw is goed in staat zichzelf te vermaken, onder andere met een muziekinstrument. Activiteiten met anderen in een groep stelt zij niet op prijs. Naar aanleiding van het doornemen van de RAP voor Activiteiten wordt door de hulpverleners opgemerkt dat mw. steeds minder uitdagingen aangaat en dat nieuwe mogelijkheden voor individuele activiteiten met haar zullen worden doorgenomen (o.a. gebruik van e-mail en Internet).

Ad 4: Het eerste item (stelt zich eigen doelen) is een positief geformuleerd item: het is de bedoeling dat hiervan gebruik gemaakt wordt. De fysiotherapeut meldt hierop dat mevrouw F haar heeft gezegd weer therapie te willen. Ze stelt voor om met mevrouw F de te behalen doelen voor fysiotherapie te bespreken.

Ad 5: Deze lichte cognitieve problemen zijn sinds het CVA bekend, ze zijn neuropsychologisch onderzocht en tot nu toe stabiel gebleken. Het is wel belangrijk om veranderingen in deze problemen te kunnen constateren door het neuropsychologisch onderzoek te herhalen.

Dankwoord

Allereerst wil ik de leden van het management en collega's van Cascade zorgcentrum Rosendael bedanken voor de mogelijkheid die ik gekregen heb om dit werk te voltooien: zowel diegenen die mij het beginnen hebben gegund (Henk Hut, Michette Palmen, Henriet Groenendijk, Geertje Tuin en Jos Konings) als zij die mij ook het lieten afmaken (Cornelie Bosch, Ineke Bootsman, Harry Manders, Marijke Hartemink, Michelle Visser, Anja Wiepkema, Anita Wandel, Paul Schmitz en Bart Kleijer). Hans van Delden verdient een aparte vermelding, omdat hij zowel Rosendael als mij voor dit project heeft doen warmlopen. Daarnaast, Hans, heb ik veel aan je coaching (bijvoorbeeld in Jan Primus) gehad, maar nog meer aan je warme vriendschap.

Ik wil Michel en Esther bedanken voor het 'editen' van hoofdstuk 1 en 10, daarna begon ik er pas echt in te geloven.

Dinnus, jij bent onstuitbaar, en ik heb in de afgelopen jaren veel goeds aan je tomeloze energie te danken, en wil daar ook nog graag op voortbouwen.

Frank Hoek: ook al was ik niet 'van de opleiding', ik mocht toch van jullie faciliteiten en gezelligheid gebruik maken, hartelijk dank daarvoor! Ook Salomé, Henriëtte, Noortje en Karin hebben mij op meerdere momenten en op verschillende manieren geholpen, dank daarvoor.

Debby, dank voor je commentaar op concepten, daar had ik altijd veel aan. Maar ook aan je gezelligheid en steun, in de kroeg in Rolduc of San Diego tot bij de koffieautomaat van de VU. Lineke en Martin: jullie zijn erg prettige, attente en inspirerende VU-collega's: ik waardeer jullie erg en hoop nog veel met jullie te kunnen samenwerken.

Zonder de verpleeghuisartsen in opleiding die de gegevens van 562 patiënten hebben verzameld kon het onderzoek in hoofdstukken 6-9 niet gedaan worden. Jullie inspanningen zijn door mij erg gewaardeerd.

De leden van de leescommissie: Jouke van der Zee, Jos Schols, Rianne de Wit, Dorly Deeg, Aart Jan Beekman en John Morris wil ik bedanken voor het kritisch beoordelen van het manuscript.

Dank gaat vanzelfsprekend uit naar mijn promotor, Miel Ribbe: Miel, je hebt met je enthousiasme de verpleeghuisgeneeskunde bemest en bewaterd, en er is nu niet alleen een mooi beroep met goede opleidingen, maar je hebt ondertussen ook velen ingewijd in de verpleeghuiswetenschap. Ik ben er trots op dat ik bij je steeds groter wordende schare van gepromoveerden mag worden gerekend.

Anne Margriet Pot en Ada Kerkstra, mijn co-promotoren, jullie waren voor mij een gouden stel. Anne Margriet, zelfs tijdens mijn opleiding was je al mijn begeleider, en dat heb je altijd met enthousiasme en een grote degelijkheid en persoonlijke betrokkenheid gedaan. Dat we samen nog maar veel artikelen mogen schrijven! Ook jij, Ada, hebt zich altijd met veel kennis, kunde en empathie met mij en mijn beslommeringen bemoeit. Zelfs toen je bij de Inca's met een nare griep zat, las jij mijn stukken tussen twee koortspieken door, in de schaduw van een tempelruïne.

Naast deze begeleiders heb ik bij het schrijven van enkele hoofdstukken ook veel gehad aan de scherpzinnigheid van Marcel Ooms, Rob Scholten, Jos Twisk en Erik Scherder.

David Mehr, ook jij bedankt voor je tijd en inzet, het is jammer dat we nog geen project samen hebben kunnen doen, wellicht in de toekomst?

I wish to thank all interRAI members, but especially Brant Fries and John Morris, who are always willing to help a curious Dutch PhD student.

Chantal, Roeline, Jenny, jullie interesse voor mij en mijn onderzoek en de samenwerking waren erg prettig. En daarnaast: een goed voorbeeld doet goed volgen.

Tot slot, Nicole, Max, Jim en alle vrienden die ons met warmte omhullen: dat wij elkaar gevonden hebben is meer dan serendipiteit. Onze liefde voor elkaar is waar alles om draait.

Curriculum Vitae

Wilco Achterberg werd op 6 december 1963 in Zeist geboren. Van 1975 tot 1981 doorliep hij het Gymnasium van scholengemeenschap Schoonoord (Zeist), waarna hij in Utrecht Geneeskunde ging studeren. In 1989 werd hij arts, en na gewerkt te hebben in het ziekenhuis (longziekten en interne geneeskunde) vond hij in 1992 zijn plek in het verpleeghuis. In 1996 voltooide hij de opleiding tot verpleeghuisarts aan de Vrije Universiteit en RK Zorgcentrum Sint Jacob te Amsterdam. Hij werkt sindsdien als verpleeghuisarts in Cascade Zorgcentrum Rosendael te Utrecht. Rosendael heeft hem sinds 1997 voor 1 dag in de week vrijgesteld voor het doen van wetenschappelijk onderzoek (dat is beschreven in dit proefschrift) en het volgen van de opleiding tot epidemioloog. Het EMGO-instituut/afdeling verpleeghuisgeneeskunde van de Vrije Universiteit heeft hem de ruimte en faciliteiten gegeven (en blijft dat voorlopig doen) voor het uitvoeren van wetenschappelijk onderzoek.

Daarnaast is Wilco hoofdredacteur van het Tijdschrift voor Verpleeghuisgeneeskunde.

Hij is getrouwd met Nicole, en heeft twee lieve zonen: Max (7) en Jim (4).

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Identificatienummer_____

MINIMUM DATA SET (MDS) — *VERSIE 2.0*

VOOR BEOORDELING EN ZORGBEPALING VAN VERPLEEGHUISPATIËNTEN

SECTIE AA. IDENTIFICATIE-INFORMATIE (*Moet altijd worden ingevuld*)

1. NAAM PATIËNT

a. (Voornaam) **b.** (Initialen) **c.** (Achternaam)

2. GESLACHT

1. Man 2. Vrouw

3. GEBOORTE-DATUM

Dag — Maand — Jaar

5. ZORGVER-ZEKERAAR EN POLISNR

a. Verzekeraar: _____

b. Polisnummer:

6. CODE VERPLEEG-HUIS

7. IDENTIFICA-TIE

a. Uniek identificatienummer:

b. Kamernummer:

c. Afdelingsnummer:

8. REDENEN VOOR BEOORDE-LING

a. Belangrijkste reden voor beoordeling
1. Beoordeling bij eerste opname (moet op dag 14 zijn uitgevoerd)
2. Jaarlijkse beoordeling
3. Beoordeling vanwege een wezenlijke toestandsverandering
4. Wezenlijke correctie van een eerdere beoordeling
5. Kwartaalbeoordeling (***apart formulier voor Secties A t/m R***)
6. Ontslag—geen heropname voorzien
7. Ontslag—heropname voorzien
8. Ontslag voordat de eerste beoordeling klaar was
9. Heropname
0. *GEEN VAN BOVENSTAANDE*

b. ***Speciale codes voor wanneer om een of andere reden op een afwijkend tijdstip een volledige beoordeling wordt uitgevoerd***
1. *5-de dag beoordeling*
2. *30-ste dag beoordeling*
3. *60-ste dag beoordeling*
4. *Kwartaalbeoordeling met invulling van volledig MDS*
5. *Heropnamebeoordeling*
6. *Anders*

9. EERSTE OPNAME GEGEVENS

(***Eenmalig bij eerste invulling, indien mogelijk bij eerste opname***)

a. Datum van eerste opname:

Dag — Maand — Jaar

b. Opgenomen vanuit (bij eerste opname):
1. Eigen omgeving zonder thuiszorg
2. Eigen omgeving met thuiszorg
3. Verzorgingshuis
4. Verpleeghuis
5. Algemeen ziekenhuis
6. Psychiatrisch ziekenhuis, instelling voor geestelijk gehandicapten
7. Revalidatiecentrum
8. Anders

10. HEROPNAME GEGEVENS

(***Alleen bij heropname***)

a. Datum van heropname:

Dag — Maand — Jaar

b. Opgenomen vanuit (bij heropname):
1. Eigen omgeving zonder thuiszorg
2. Eigen omgeving met thuiszorg
3. Verzorgingshuis
4. Verpleeghuis
5. Algemeen ziekenhuis
6. Psychiatrisch ziekenhuis, instelling voor geestelijk gehandicapten
7. Revalidatiecentrum
8. Anders

11. ONTSLAG GEGEVENS

(***Alleen bij ontslag–ook overlijden***)

a. Datum van ontslag of overlijden:

Dag — Maand — Jaar

ONTSLAG GEGEVENS (***Vervolgd***)

b. Verblijfssituatie bij ontslag:
1. Naar eigen omgeving zonder thuiszorg dienstverlening
2. Naar eigen omgeving met thuiszorg dienstverlening
3. Verzorgingshuis
4. Ander verpleeghuis
5. Algemeen ziekenhuis
6. Psychiatrisch ziekenhuis, instelling voor geestelijk gehandicapten
7. Revalidatie-ziekenhuis
8. Overleden
9. Anderszins

12. DEELNAME AAN DE BEOOR–DELING

a. Patiënt: 0. Nee 1. Ja
b. Familie: 0. Nee 1. Ja 2. Heeft geen familie
c. Belangrijk ander persoon: 0. Nee 1. Ja 2. Geen

13. HANDTEKENINGEN VAN HEN DIE DE BEOORDELING HEBBEN UITGEVOERD:

a. Handtekening van de beoordeling coördinerende verpleegkundige (teken hierboven)

b. Datum van handtekening

Dag — Maand — Jaar

c. Andere Handtekeningen — Functie — Secties — Datum

d. — Datum

e. — Datum

f. — Datum

g. — Datum

h. — Datum

☐ = Indien blanco, vul dan een getal of letter in **a.** = Indien met letter, kruis dan het antwoord aan dat van toepassing is

Patiënt _____ Identificatienummer_____

SECTIE AB. PERSOONSGEGEVENS (*Eenmalig bij eerste invulling, indien mogelijk bij eerste opname*)

1.	**WOONDE (VOOR 1E OPNAME) ALLEEN**	0. Nee 1. Ja 2. In andere instelling	
2.	**POSTCODE (VOOR 1E OPNAME)**		
3.	**VOOR-AFGAAND VERBLIJF IN INSTEL-LINGEN IN DE LAATSTE 5 JAAR**	(***Kruis de instellingen aan*** *waar de patiënt de laatste 5 jaar voorafgaand aan de eerste opname, zie item AB1,* ***woonde****)*	
		Eerder verblijf in dit verpleeghuis	a.
		Verblijf in een ander verpleeghuis	b.
		Verblijf in andere instelling --Pensiontehuis, verzorgingshuis, begeleid wonen, groepstehuis	c.
		Psychiatrische zorgsetting	d.
		Zorgsetting voor geestelijk gehandicapten	e.
		GEEN VAN BOVENSTAANDE	f.
4.	**VROEGERE BEROEP(EN) [Zet "/" tussen twee beroepen]**		
5.	**OPLEIDING (*Hoogst behaalde niveau*)**	1. Geen scholing 2. Lagere school/minder 3. MAVO/HAVO of vergelijkbaar 4. VWO 5. MBO 6. HBO 7. Universitaire opleiding	
6.	**TAAL**	(*Codeer het juiste antwoord*)	
		a. Moedertaal	
		0. Nederlands 1. Andere taal	
		b. Indien andere taal, specificeer:	
7.	**GEESTE-LIJKE GEZONDHEID**	Vermeldt het patiëntDOSSIER een geestelijke handicap, geestesziekte of enig andere ontwikkelingsbeperking? 0. Nee 1. Ja	
8.	**ZIEKTE-BEELDEN DIE SAMEN-HANGEN MET GEESTE-LIJKE HANDICAP**	(***Kruis de ziektebeelden aan*** *die samenhangen met de geestelijke handicap, optraden voor het 22-ste jaar, en waarschijnlijk blijvend zijn*)	
		N.v.t. —geen geestelijke handicap (Ga direct naar AB11)	a.
		Geestelijke handicap van organische aard:	
		Down's syndroom	b.
		Autisme	c.
		Epilepsie	d.
		Ander organisch ziektebeeld in verband met geestelijke handicap	e.
		Geestelijke handicap niet organisch	f.

SECTIE AC. GEWOONTEN ROUTINE (*Eenmalig bij eerste invulling, indien mogelijk bij eerste opname*)

1.	**GEWOONTEN ROUTINE** ***(In het jaar voorafgaand aan DE DATUM VAN EERSTE OPNAME in dit verpleeg-huis, of het laatste jaar thuis indien opgenomen vanuit een ander verpleeghuis of verpzorgings-huis)***	(***Kruis aan.*** *Bij alles ONBEKEND, kruis dan alleen het laatste hokje aan.*)	
		DAGRITME	
		Bleef 's avonds laat op (bijv. tot na 9 uur)	a.
		Sliep regelmatig overdag (tenminste 1 uur)	b.
		Ging tenminste 1x per week uit	c.
		Hield zich bezig met hobby's, lezen of andere vaste dagroutine	d.
		Was meestal alleen of keek meestal televisie	e.
		Verplaatste zich zelfstandig binnenshuis (evt. met hulpmiddelen)	f.
		Gebruikte tenminste dagelijks tabaksproducten	g.
		GEEN VAN BOVENSTAANDE	h.
		EETGEWOONTEN	
		Had voorkeur voor bepaald voedsel	i.
		At elke dag of de meeste dagen tussendoor	j.
		Dronk minstens 1x per week alcohol	k.
		GEEN VAN BOVENSTAANDE	l.
		ADL-GEWOONTEN	
		Liep een groot deel van de dag in nachtkleding	m.
		Stond bijna elke nacht op om naar het toilet te gaan	n.
		Had een onregelmatige stoelgang	o.
		Nam een bad in plaats van een douche	p.
		Nam een douche of bad in de middag of avond	q.
		GEEN VAN BOVENSTAANDE	r.
		BETROKKENHEID	
		Had dagelijks contact met familie/vrienden	s.
		Ging vaak naar de kerk, moskee, synagoge (enz.)	t.
		Putte kracht uit het geloof	u.
		Huisdier als dagelijks gezelschap	v.
		Nam deel aan groepsactiviteiten	w.
		GEEN VAN BOVENSTAANDE	x.
		ONBEKEND—Patiënt/familie niet in staat om informatie te geven	y.

Patiënt _____ Identificatienummer _____

MINIMUM DATA SET (MDS) — *VERSIE 2.0*
VOOR BEOORDELING EN ZORGBEPALING VAN VERPLEEGHUISPATIENTEN
FORMULIER VOOR EEN VOLLEDIGE BEOORDELING

(Toestand in de laatste 7 dagen, tenzij een ander tijdsbestek is aangegeven)

SECTIE A. IDENTIFICATIE- EN ACHTERGROND-INFORMATIE

3. BEOORDELINGS REFERENTIE-DATUM

a. *Einddatum MDS observatieperiode*

Dag — Maand — Jaar

b. Oorspronkelijk (0) of zoveelste gecorrigeerd formulier (vul getal in)

5. BURGERLIJKE STAAT

1. Nooit gehuwd 3. Partner/significant andere 5. Uiteen
2. Gehuwd 4. Verweduwd 6. Gescheiden

9. VERANTWOORDELIJKHEID/ VOOGD

(***Kruis aan***)

- Voogd — a.
- Ander wettelijk toezicht — b.
- Curator: gezondheidzorg — c.
- Curator: financieel — d.
- Familielid verantwoordelijk — e.
- Patiënt zelf verantwoordelijk — f.
- *GEEN VAN BOVENSTAANDE* — g.

10. AFGEGEVEN BESCHIKKINGEN

(***Kruis*** *de items* ***aan*** *waar in het medisch dossier iets over staat* ***opgetekend***)

- Levenstestament — a.
- Niet reanimeren — b.
- Niet naar ziekenhuis — c.
- Donorcodicil — d.
- Verzoek om autopsie — e.
- Voedingsbeperkingen — f.
- Beperkingen bij medicijntoediening — g.
- Andere behandelbeperkingen — h.
- *GEEN VAN BOVENSTAANDE* — i.

SECTIE B. COGNITIEF FUNCTIONEREN

1. COMATEUS

(*Voortdurende vegatieve toestand/ niet waarneembaar bewustzijn*)

0. Nee 1. Ja (**Ja, ga dan direct naar Sectie G**)

2. GEHEUGEN/ PASSIEF

(*Zich herinneren wat vroeger geleerd is of bekend was*)

a. Korte-termijn geheugen —schijnt/lijkt na 5 min. nog te herinneren
0. Geheugen goed 1. Geheugenprobleem

b. Lange-termijn geheugen—schijnt/lijkt verre verleden te herinneren
0. Geheugen goed 1. Geheugenprobleem

3. GEHEUGEN/ ACTIEF

(***Kruis aan*** *hetgeen de patiënt zich* ***gewoonlijk gedurende de laatste 7 dagen kon herinneren***)

- Huidig jaargetij — a.
- Ligging eigen kamer — b.
- Namen/gezichten verzorg — c.
- Dat hij/zij in een verpleeghuis is — d.
- *GEEN VAN BOVENSTAANDE* — e.

4. COGNITIEVE VAARDIGHEDEN VOOR DE DAGELIJKSE BESLUITVORMING

(*Nam beslissingen over taken van dagelijks leven*)

0. *ZELFSTANDIG*—beslissingen samenhangend/redelijk
1. *VERMINDERD ZELFSTANDIG*—slechts in nieuwe situaties enige moeite
2. *MATIG GESTOORD*—slechte beslissingen; aanwijzingen/toezicht nodig
3. *ERNSTIG GESTOORD*—nam zelden of nooit beslissingen

5. INDICATOREN VAN DELIER—PERIODIEK GESTOORD DENKEN/ BEWUST-ZIJN

(*Codeer het gedrag van de* ***laatste 7 dagen.)***

0. Gedrag niet aanwezig
1. Gedrag aanwezig, maar niet recent begonnen
2. Gedrag aanwezig, bewoner lijkt de laatste 7 dagen anders te functioneren (bv., gedrag is net begonnen of erger geworden)

a. GEMAKKELIJK AFGELEID—(bv., moeite met aandacht opbrengen; raakt gemakkelijk op dwaalspoor)

b. WAARNEMEN, BEWUSTZIJN VAN OMGEVING WISSELEND—(bv. beweegt de lippen of praat tegen een niet-aanwezig persoon; denkt ergens anders te zijn; haalt de dag en de nacht door elkaar)

c. EPISODEN VAN ONSAMENHANGEND PRATEN—(bv., spraak mist samenhang, is onzinnig, niet ter zake, of gaat van de hak op de tak; raakt de gedachtengang kwijt)

d. PERIODEN VAN ONRUST—(bv., frunikken of krabben aan de huid, aan kleding, servetten, enz.; vaak van lichaamshouding veranderen; herhaald bewegingen uitvoeren of schreeuwen)

e. PERIODEN VAN LUSTELOOSHEID—(bv., sloom zijn; voor zich uit staren; moeilijk wakker te krijgen; weinig lichaamsbeweging)

f. GEESTELIJK FUNCTIONEREN WISSELT GEDURENDE DAG—(bv., soms beter, soms slechter; gedrag soms wel, soms niet)

6. VERANDERING COGNITIEF FUNCTIONEREN

De cognitieve toestand, vaardigheden of vermogens van de patiënt zijn ten opzichte van **90 dagen geleden** (of sinds de laatste beoordeling daarna) veranderd

0. Geen verandering 1. Verbeterd 2. Verslechterd

SECTIE C. COMMUNICATIEPATRONEN/GEHOOR

1. HOREN

(*met gehoorapparaat, indien gebruikt*)

0. *HOORT NAAR BEHOREN*—normaal gesprek, TV, telefoon
1. *ENIGSZINS MOEITE* wanneer het niet rustig is
2. *HOORT SLECHTS IN SPECIALE OMSTANDIGHEDEN*—spreker moet toonhoogte aanpassen en duidelijk spreken
3. *ERNSTIG GESTOORD*/bruikbare gehoorfunctie afwezig

2. COMMUNICATIE-HULPMIDDELEN/ TECHNIEKEN

(***Kruis aan*** *wat gedurende de laatste 7 dagen van toepassing is*)

- Gehoorapparaat, aanwezig en gebruikt — a.
- Gehoorapparaat, aanwezig, maar niet regelmatig gebruikt — b.
- Gebruikt andere communicatietechnieken (bv., liplezen) — c.
- *GEEN VAN BOVENSTAANDE* — d.

3. MANIEREN VAN ZICH UITEN

(***Kruis aan*** *hoe patiënt behoeften kenbaar maakt*)

- Spreken — a.
- Schrijven van een briefje — b.
- Officiële gebarentaal of BRAILLE — c.
- Tekens/gebaren/geluiden — d.
- Communicatiebord — e.
- Anderszins — f.
- *GEEN VAN BOVENSTAANDE* — g.

4. ZICHZELF DUIDELIJK MAKEN

(*Maakt de inhoud van boodschap duidelijk—hoe dan ook*)

0. *WORDT BEGREPEN*
1. *GEWOONLIJK BEGREPEN*—moeite bij het vinden van woorden of het afmaken van gedachten
2. *SOMS BEGREPEN*—kan alleen concrete verzoeken doen
3. *WORDT ZELDEN OF NOOIT BEGREPEN*

5. DUIDELIJKHEID VAN SPREKEN

(*Codeer het spreken in de* ***laatste 7 dagen***)

0. *DUIDELIJK SPREKEN*—duidelijke, verstaanbare woorden
1. *ONDUIDELIJK SPREKEN*—slissen, mompelen
2. *SPREEKT NIET*—geen gesproken woorden

6. VERMOGEN OM ANDEREN TE BEGRIJPEN

(*Begrijpen van verbale informatie—hoe dan ook*)

0. *BEGRIJPT*
1. *BEGRIJPT GEWOONLIJK*—kan een deel of de bedoeling van de boodschap missen
2. BEGRIJPT SOMS—geeft passende reactie op eenvoudige, directe communicatie
3. *BEGRIJPT ZELDEN OF NOOIT*

7. VERANDERING COMMUNICATIE/ HOREN

Het vermogen van de patiënt zich te uiten, te begrijpen of informatie te horen is vergeleken met **90 dagen geleden** (of sinds de laatste beoordeling daarna) veranderd

0. Geen verandering 1. Verbeterd 2. Verslechterd

SECTIE D. GEZICHTSVERMOGEN

1. KUNNEN ZIEN

(*Gezichtsvermogen bij voldoende licht, eventueel met bril*)

0. *VOLDOENDE*—ziet details, kan alle letters in kranten en boeken lezen
1. *BEPERKT*—ziet wel grote, maar niet drukletters van normale grootte
2. *MATIG BEPERKT*—beperkt gezichtsvermogen, kan geen krantenkoppen zien, maar kan wel voorwerpen herkennen
3. *STERK BEPERKT*—het is de vraag of voorwerpen worden herkend, maar de ogen lijken wel voorwerpen te volgen
4. *ZEER ERNSTIG BEPERKT*—ziet niets of alleen licht, kleuren of vormen; ogen lijken geen voorwerpen te volgen

2. GEZICHTSBEPERKING/ MOEILIJKHEDEN

- Gezichtsveldproblemen—verminderd perifeer zien (bv., laat voedsel op één helft van dienblad liggen, botst tegen mensen en voorwerpen op, heeft moeite om stoel te vinden bij het gaan zitten) — a.
- Ervaart iets van het volgende: ziet kransen of ringen rond licht–bronnen; lichtflitsen; "waas" voor de ogen — b.
- *GEEN VAN BOVENSTAANDE* — c.

3. GEZICHTSMIDDELEN

Bril; contactlenzen; vergrootglas
0. Nee 1. Ja

Patiënt _____ Identificatienummer _____

SECTIE E. STEMMINGS- EN GEDRAGSPATRONEN

1. INDICATOREN VAN DEPRESSIE, ANGST, BEDROEFDE STEMMING

(***Codeer de in de laatste 30 dagen waargenomen aanwijzingen, ongeacht de vermoedelijke oorzaak***)
0. Indicator in de laatste 30 dagen niet vertoond
1. Indicator van dit type 1 tot 5 dagen per week vertoond
2. Indicator dagelijks of bijna dagelijks vertoond (6, 7 dagen per week)

VERBALE UITINGEN VAN LIJDEN

a. Negatieve uitspraken—"*Het doet er allemaal niet toe; Was ik maar dood; Wat voor zin heeft het; Het spijt me zolang te hebben geleefd; Laat me sterven*"

b. Aldoor vragen—"*Waar ga ik heen; Wat doe ik dan?*"

c. Aldoor uitroepen—Om hulp roepen, ("*God sta me bij*")

d. Voortdurend boos zijn op zichzelf of op anderen—Zich gemakkelijk ergeren, boos op verblijf in verpleeghuis; boos op de ontvangen zorg

e. Zelfverwijt—"*Ik ben niets; Ik ben niemand tot nut*"

f. Uitingen van angst die niet reëel lijken—Bang om in de steek te worden gelaten, alleen te zijn, samen met anderen te zijn

g. Aldoor zeggen dat iets vreselijks gaat gebeuren—Denken dat men op het punt staat dood te gaan, een hartaanval heeft

h. Aldoor klagen over gezondheid—Om de dokter blijven vragen, obsessief bezorgd zijn over lichaamsfuncties

i. Aldoorr zorgelijk klagen (niet met gezondheid samenhangend)—Zoekt steeds aandacht/geruststelling over de dagindeling, maaltijden, de was, kleren, de omgang met anderen

SLAAPPROBLEMEN

j. Ochtendhumeur

k. Slapeloosheid/ verandering in gebruikelijk slaappatroon

BEDROEFD, ANGSTIG, APATHISCH UITERLIJK

l. Droevige, pijnlijke, zorglijke gelaatsuitdrukking—Diepe rimpels

m. Huilen, gemakkelijk tranen

n. Motorische onrust—IJsberen, handenwringen, rusteloos zijn, friemelen, plukken

INTERESSEVERLIES

o. Terugtrekken uit activiteiten—Geen interesse meer in wat men altijd deed of met familie/vrienden zijn

p. Minder omgang

2. HARDNEKKIGE STEMMINGSSTOORNIS

Een of meer aanwijzingen van droevige of angstige stemming die **in de laatste 7 dagen niet gemakkelijk door "opvrolijken", troosten of geruststellen waren te veranderen**
0. Geen aanwijzingen 1. Aanwijzingen, maar makkelijk veranderd 2. Aanwijzingen, niet makkelijk veranderd

3. VERANDERING STEMMING

De gemoedstoestand van de patiënt is ten opzichte van **90 dagen geleden** (of sinds de laatste beoordeling daarna) veranderd
0. Geen verandering 1. Verbeterd 2. Verslechterd

4. GEDRAGSSYMPTOMEN

(A) ***De frequentie van het gedrags****symptoom* ***in de laatste 7 dagen***
0. Gedrag kwam in de laatste 7 dagen niet voor
1. Gedrag kwam 1 tot 3 dagen in de laatste 7 dagen voor
2. Gedrag kwam 4 tot 6 dagen voor, maar niet elke dag
3. Gedrag kwam dagelijks voor

(B) ***De veranderbaarheid van het gedrags****symptoom* ***de laatste 7 dagen***
0. Gedrag afwezig OF gedrag gemakkelijk veranderd
1. Gedrag was niet gemakkelijk te veranderen

	(A)	(B)
a. ZWERFGEDRAG (liep doelloos rond, zich schijnbaar niet bewust van behoeften of gevaar)		
b. VERBAAL LASTIGVALLEN (bedreigde anderen, schreeuwde naar ze, vloekte naar ze)		
c. LICHAMELIJK LASTIGVALLEN (sloeg anderen, duwde, krabde, viel seksueel lastig)		
d. SOCIAAL ONAANGEPAST/STOREND GEDRAG (maakte storende geluiden, lawaai, gegil, zelfverwonding, vertoonde seksueel gedrag of kleedde zich in het openbaar uit, smeerde/ gooide met eten/feces, hamsterde, snuffelde in andermans spullen)		
e. VERZET TEGEN ZORG (weigerde medicijnen/ injecties, hulp bij ADL of bij eten)		

5. VERANDERING GEDRAG

De gedragstoestand van de patiënt is ten opzichte van **90 dagen geleden** (of sinds de laatste beoordeling daarna) veranderd
0. Geen verandering 1. Verbeterd 2. Verslechterd

SECTIE F. PSYCHOSOCIAAL WELBEVINDEN

1. GEVOEL VAN INITIATIEF/ BETROKKENHEID	Op gemak in omgang met anderen	**a.**
	Op gemak bij geplande of gestructureerde activiteiten	**b.**
	Op gemak bij zelf-opgezette activiteiten	**c.**
	Stelt zich eigen doelen	**d.**
	Zoekt betrokkenheid in instelling (maakt/houdt vrienden; neemt deel aan groepsactiviteiten; nieuwe activiteiten; helpt bij activiteiten van godsdienstige aard	**e.**
	Neemt uitnodigingen aan voor de meeste groepsactiviteiten	**f.**
	GEEN VAN BOVENSTAANDE	**g.**
2. ONGEMAKKELIJKE OMGANG MET ANDEREN	Bedekt/openlijk conflict met of herhaalde kritiek op zorgverleners	**a.**
	Niet blij met kamergenoot	**b.**
	Niet blij met andere patiënten dan kamergenoot	**c.**
	Uit openlijk conflict/boosheid met familie/vrienden	**d.**
	Geen persoonlijk contact met familie/vrienden	**e.**
	Recent verlies van naast familielid/vriend	**f.**
	Past zich niet gemakkelijk aan veranderende routines aan	**g.**
	GEEN VAN BOVENSTAANDE	**h.**
3. VROEGERE ROLLEN	Sterke vereenzelviging met vroegere rollen en status	**a.**
	Uit droefheid/boosheid/leegte over verloren rollen/status	**b.**
	Patiënt ervaart de dagelijkse routine (gewoonten, activiteiten) als geheel verschillend van vroeger thuis	**c.**
	GEEN VAN BOVENSTAANDE	**d.**

SECTIE G. LICHAMELIJK FUNCTIONEREN EN STRUCTURELE PROBLEMEN

1. (A) ZELF-DOEN BIJ ADL—(***Codeer het ZELF-DOEN*** *van de patiënt* ***IN ALLE DIENSTEN gedurende de laatste 7 dagen****—Niet het gereedzetten van dingen*)

0. *ZELFSTANDIG*—Geen hulp of toezicht —OF— Hulp/toekijken slechts 1 of 2 keer gedurende de laatste 7 dagen
1. TOEZICHT—Toekijken, aanmoediging of aanwijzingen 3 of meer keer gedurende de laatste 7 dagen —OF— Toezicht (3 of meer keer) plus slechts 1 of 2 keer lichamelijke ondersteuning gedurende de laatste 7 dagen
2. *BEPERKTE HULP*—Patiënt erg betrokken bij activiteit; ontving 3 of meer keer lichamelijke hulp bij het manoeuvreren van ledematen of ontving andere niet-gewichtsontlastende hulp —OF—Meer hulp slechts 1 of 2 keer gedurende de laatste 7 dagen
3. *UITGEBREIDE HULP*—Terwijl de patiënt een deel van de activiteit zelf uitvoerde, werd de volgende hulp in de laatste 7 dagen 3 keer of vaker gegeven:
— Gewichtsontlastende hulp
— Hulp geheel door zorgverleners uitgevoerd, maar niet gedurende alle 7 dagen
4. *TOTAAL AFHANKELIJK*—Geheel door zorgverleners uitgevoerd gedurende 7 dagen
8. *ACTIVITEIT KWAM* gedurende de gehele 7 dagen NIET VOOR

(B) DE GEGEVEN ADL-HULP—(***Codeer de MAXIMAAL GEGEVEN HULP IN ALLE DIENSTEN gedurende de laatste 7 dagen; codeer ongeacht*** *het vastgelegde zelf-doen van de patiënt*)

0. Zonder klaarzetten of lichamelijke hulp door zorgverleners
1. Slechts hulp in de vorm van klaarzetten
2. Lichamelijke hulp door 1 persoon
3. Lichamelijke hulp door 2 of meer personen
8. Activiteit kwam tijdens de gehele 7 dagen niet voor

			(A) ZELF-DOEN	(B) HULP
a.	**BEWEEGLIJKHEID IN BED**	Hoe patiënt uit/in de lighouding komt, zich omdraait, en in bed de lichaamshouding aanneemt		
b.	**TRANSFER**	Hoe de patiënt tussen oppervlakten beweegt—in/uit bed, stoel, rolstoel, staan (NIET in/uit bad/toilet)		
c.	**LOPEN IN DE KAMER**	Hoe de patiënt van plek naar plek in zijn/haar kamer loopt		
d.	**LOPEN OP DE GANG**	Hoe de patiënt op de gang van de afdeling loopt		
e.	**VERPLAATSEN OP AFDELING**	Hoe de patiënt zich van plaats tot plaats in zijn/haar kamer en de gang ernaast op dezelfde verdieping begeeft. Bij gebruik van rolstoel, hoe zelfstandig daarmee		
f.	**VERPLAATSEN BUITEN DE AFDELING**	Hoe de patiënt zich naar buiten de afdeling begeeft en terugkeert (bv., eet-, activiteiten- of behandelruimten). **Als er maar één verdieping is**, hoe de patiënt dan naar verafgelegen ruimten gaat. Bij gebruik van rolstoel, hoe zelfstandig de patiënt daarmee is		
g.	**KLEDEN**	Hoe de patiënt alle **uitgaanskledingstukken** aantrekt, dichtknoopt, uittrekt, inclusief het aan-/uitdoen van een prothese		
h.	**ETEN**	Hoe de patiënt eet en drinkt (ongeacht vaardigheid). Dit omvat ook het nuttigen van voedsel op ander manieren (bv., sondevoeding, totale parenterale voeding)		
i.	**TOILETGEBRUIK**	Hoe de patiënt de toiletruimte (of toiletstoel, pot, urinaal) gebruikt; op/van het toilet komt, doorspoelt, luier wisselt, omgaat met stoma/ catheter, kleren in orde brengt		
j.	**PERSOONLIJKE HYGIENE**	Hoe de patiënt de persoonlijke hygiëne handhaaft, inclusief haarkammen, tanden poetsen, scheren, makeup aanbrengen, gezicht, handen en bilnaad wassen/drogen (NIET baden en douchen)		

2. BADEN

Hoe de patiënt in bad gaat/doucht, zich afsponst en in/uit bad of douche komt (NIET het wassen van rug en haar.) ***Codeer de grootste afhankelijkheid*** *bij het zelf-doen en bij hulp.*

(A) De ZELF-DOEN codes hierbij zijn:

0. Zelfstandig—Geen hulp gegeven
1. Toezicht—Alleen maar toekijk-hulp
2. Lichamelijke hulp beperkt tot transfers
3. Lichamelijke hulp bij gedeelte van baadactiviteit
4. Totale afhankelijkheid
8. Activiteit kwam gedurende de gehele 7 dagen niet voor

(*Codes voor hulp bij baden, zie* ***item 1, code B***)

Patiënt _____ Identificatienummer _____

3. TEST VOOR EVENWICHT (zie Gebruikers-handboek)

(*Codeer wat de patiënt in de **laatste 7 dagen*** kon)

0. Handhaafde stand zoals in de test vereist
1. Wankelde, maar was in staat om zonder hulp het evenwicht te hervinden
2. Gedeeltelijke lichamelijke ondersteuning tijdens test; of gaat staan (zitten) maar niet zoals de test dat verlangt
3. Niet in staat om de test te doen zonder lichamelijke hulp

a. Evenwicht bij staan
b. Evenwicht bij zitten—houding, controle over het bovenlijf

4. FUNCTIONELE BEWEGINGS-BEPERKING (zie Gebruikers-handboek)

(*Codeer de beperkingen gedurende de **laatste 7 dagen** die de dagelijkse functies belemmerden of een risico voor verwondingen vormden*)

(A) *BEWEGINGSUITSLAG*
0. Geen beperking
1. Beperking aan één kant
2. Beperking aan beide kanten

(B) *WILLEKEURIGE BEWEGING*
0. Geen verlies
1. Gedeeltelijk verlies
2. Volledig verlies

	(A)	(B)
a. Nek		
b. Arm—Inclusief schouder of elleboog		
c. Hand—Inclusief pols of vingers		
d. Been—Inclusief heup of knie		
e. Voet—Inclusief enkel of tenen		
f. Andere beperking of verlies		

5. MANIEREN VAN ZICH VERPLAATSEN

(***Kruis aan** wat gedurende de **laatste 7 dagen van toepassing is***)

Stok/rollator/kruk **a.**
Zelfvoortbewogen rolstoel **b.**
In rolstoel geduwd **c.**
Rolstoel belangrijkste manier om zich te verplaatsen **d.**
GEEN VAN BOVENSTAAND **e.**

6. MANIEREN VAN TRANSFER

(***Kruis aan** wat gedurende de **laatste 7 dagen van toepassing is***)

Altijd of meestal in bed **a.**
Bedhekken voor beweeglijkheid in bed of bij transfers **b.**
Met de hand getild **c.**
Mechanische getild **d.**
Hulpmiddel (bv. glijplank, papegaai, stok, driepoot, tuigje) **e.**
GEEN VAN BOVENSTAAND **f.**

7. TAAK-OPDELING

Sommige of alle ADL-activiteiten werden gedurende de **laatste 7 dagen** in deeltaken opgedeeld zodat de patiënt ze kon uitvoeren
0. Nee 1. Ja

8. POTENTIEEL VOOR ADL-REVALIDATIE

Patiënt denkt dat hij/zij is in staat is tot grotere zelfstandigheid in tenminste enkele van de ADL's **a.**
De directe zorgverleners denken dat de patiënt in staat is tot grotere zelfstandigheid in tenminste enkele van de ADL's **b.**
De patiënt kan taken/activiteiten uitvoeren, maar is erg langzaam **c.**
Er is een verschil in zelf-doen bij ADL of Hulp bij ADL in de ochtend ten opzichte van de avond **d.**
GEEN VAN BOVENSTAANDE **e.**

9. VERANDERING FUNCTIONEREN BIJ ADL

Het zelf-doen bij ADL van de patiënt is ten opzichte van **90 dagen geleden** (of sinds de laatste beoordeling daarna) veranderd
0. Geen verandering 1. Verbeterd 2. Verslechterd

SECTIE H. CONTINENTIE IN DE LAATSTE 14 DAGEN

1. CONTINENTIEZELFBEHEERSING CATEGORIEËN
(***Codeer het DOEN VAN DE PATIËNT OVER ALLE DIENSTEN HEEN***)

0. *CONTINENT*—Volledige beheersing *[inbegrepen het gebruik van een verblijfscatheter of stoma die geen urine of feces lekken]*

1. *GEWOONLIJK CONTINENT*—BLAAS, incontinentie-gebeurtenissen een keer per week of minder; DARMEN, minder dan een keer per week

2. *AF EN TOE INCONTINENT*—BLAAS, 2 of meer keren per week maar niet dagelijks; DARMEN, een keer per week

3. *VAAK INCONTINENT*—BLAAS, neigde naar dagelijkse incontinentie, maar enige beheersing aanwezig (bv., tijdens de dagdienst); DARMEN, 2-3 keer per week

4. *INCONTINENT*—Had ontoereikende beheersing BLAAS, dagelijks en veelvuldig; DARMEN, altijd of bijna altijd

a. CONTINENTIE VAN DE DARMEN

Beheersing over ontlasting, eventueel met hulpmiddel of dankij ontlastingsbeheersing training

b. CONTINENTIE VAN DE BLAAS

Beheersing over urineblaasfunctie (bij nalekken sijpelt er niets door de onderbroek), eventueel met hulpmidden (bv., Foley-catheter) of dankij continentie-training

2. STOELGANG

Stoelgang regelmatig—tenminste eenmaal per drie dagen **a.**
Verstopping **b.**
Diarree **c.**
Faecesprop **d.**
GEEN VAN BOVENSTAANDE **e.**

3. HULPMIDDELEN EN PROGRAMMA'S

Een toiletroosterschema **a.**
Opnieuw trainen van de blaas **b.**
Uitwendig (condoom)catheter **c.**
Verblijfscatheter **d.**
Intermitterende catheterisatie **e.**
Ging niet op toilet/toiletstoel/urinaal **f.**
Gebruikte luiers/slips **g.**
Klysma/blaasspoeling **h.**
Heeft een stoma **i.**
GEEN VAN BOVENSTAANDE **j.**

4. VERANDERING URINE-CONTINENTIE

De urine-continentie van de patiënt is ten opzichte van **90 dagen geleden** (of sinds de laatste beoordeling daarna) veranderd
0. Geen verandering 1. Verbeterd 2. Verslechterd

SECTIE I. DIAGNOSEN VAN ZIEKTEN

Kruis slechts de ziekten aan die verband houden met de huidige toestand in ADL, cognitie, stemming en gedrag, medische behandelingen, monitoring van de verpleging, of sterfterisico. (Geef geen opsomming van niet-actieve diagnosen)

1. ZIEKTEN

(***Indien géén van toepassing, dan GEEN VAN BOVENSTAAND***)

ENDOCRIEN/METABOLISME/VOEDING
Diabetes mellitus **a.**
Hyperthyreoïdie **b.**
Hypothyreoïdie **c.**
HART/BLOEDCIRCULATIE
Arteriosclerotische hartaandoening (ASHD) **d.**
Hartritmestoornissen **e.**
Decompensatio cordis **f.**
Trombose van diepe venen **g.**
Hoge bloeddruk **h.**
Lage bloeddruk **i.**
Perifere vaatziekte **j.**
Overige hart- en vaataand. **k.**
BEWEGINGSSTELSEL
Reumatische aandoeningen **l.**
Heupfractuur **m.**
Mist ledemaat (bv., amputatie) **n.**
Osteoporose **o.**
Pathologische botfractuur **p.**
NEUROLOGIE
Ziekte van Alzheimer **q.**
Afasie **r.**
Hersenverlamming **s.**
Cerebrovasculair accident (CVA/beroerte) **t.**
Dementie anders dan de ziekte van Alzheimer **u.**
Hemiplegie/Hemiparese **v.**
Multiple sclerose **w.**
Paraplegie **x.**
Ziekte van Parkinson **y.**
Quadriplegie **z.**
Toevallen (o.a. epilepsie) **aa.**
Pasagère cerebrale ischemie **bb.**
Traumatisch hersenletsel **cc.**
PSYCHIATRIE/STEMMING
Angststoornis **dd.**
Depressie **ee.**
Manisch depressief **ff.**
Schizofrenie **gg.**
ADEMHALING
Astma **hh.**
Emfyseem/COPD **ii.**
ZINTUIGEN
Cataracten **jj.**
Diabetes retinopathie **kk.**
Glaucoom **ll.**
Macula degeneratie **mm.**
OVERIGE
Allergieën **nn.**
Bloedarmoede **oo.**
Kanker **pp.**
Nierinsufficiëntie **qq.**
GEEN VAN BOVENSTAAND **rr.**

2. INFECTIES

(***Kruis aan** wat gedurende de **laatste 7 dagen van toepassing is***)

Antibiotica-resistente infectie (bv., Methicilline resistente staphilococcen) **a.**
Clostridium difficile (c. diff.) **b.**
Conjunctivitis **c.**
HIV-infectie **d.**
Pneumonie **e.**
Infectie van de luchtwegen **f.**
Sepsis **g.**
Seksueel overdraagb. aand. **h.**
Tuberculose **i.**
Urineweginfectie **in de laatste 30 dagen** **j.**
Virale hepatitis **k.**
Wondinfectie **l.**
GEEN VAN BOVENSTAAND **m.**

3. ANDERE CURRENTE OF GEDETAILLEERDERE DIAGNOSEN EN ICD-9-CM CODES

a. _____ |_|_|_|_|.|_|
b. _____ |_|_|_|_|.|_|
c. _____ |_|_|_|_|.|_|
d. _____ |_|_|_|_|.|_|
e. |_|_|_|_|.|_|

SECTIE J. GEZONDHEIDSPROBLEMEN

1. PROBLEMEN

(***Kruis alle problemen** van de **laatste 7 dagen aan** tenzij een ander tijdsbestek is aangegeven*)

VOCHTBALANS-INDICATOREN
Gewichtstoename/verlies van twee of meer kilo binnen 7 dagen **a.**
Kan niet op de rug liggen vanwege kortademigheid **b.**
Uitgedroogd; vochtverlies groter dan vochtopname **c.**
Onvoldoende vocht; nam **NIET** alle/bijna alle vocht dat in de **laatste 3 dagen** werd aangeboden **d.**
ANDERE
Wanen **e.**
Duizeligheid/draaierigheid **f.**
Oedeem **g.**
Koorts **h.**
Hallucinaties **i.**
Inwendige bloeding **j.**
Recidiverende longaspiraties in de **laatste 90 dagen** **k.**
Kortademigheid **l.**
Syncope (wegrakingen) **m.**
Onstandvastig ter been **n.**
Braken **o.**
GEEN VAN BOVENSTAAND **p.**

2. PIJN-SYMPTOMEN

(*Codeer het **hoogst** ervaren **pijnniveau** in de **laatste 7 dagen***)

a. FREQUENTIE waarmee patiënt over pijn klaagt of tekenen van pijn vertoont
0. Geen pijn (***ga naar J4***)
1. Minder dan dagelijks pijn
2. Dagelijks pijn

b. Pijn-**INTENSITEIT**
1. Lichte pijn
2. Matige pijn
3. Van tijd tot tijd vreselijke of ondraaglijke pijn

Patiënt _____ Identificatienummer _____

3.	**PLAATS VAN DE PIJN**	(*Bij pijn **kruis dan alle pijnplekken aan** van de **laatste 7 dagen***)			
		Rugpijn	a.	Pijn vanwege chirurgische wond	f.
		Botpijn	b.	Gewrichtspijn (niet heup)	g.
		Pijn in de borst terwijl men normale dingen doet	c.	Pijn aan zachte weefsels (bv., wond, spier)	h.
		Hoofdpijn	d.	Maagpijn	i.
		Pijn in de heup	e.	Andere pijn	j.
4.	**ONGE-VALLEN**	(***Kruis aan wat van toepassing is***)		Heupfractuur in de **laatste 180 dagen**	c.
		Viel in de **laatste 30 dagen**	a.	Andere fractuur in de **laatste 180 dagen**	d.
		Viel in de **laatste 31-180 dagen**	b.	*GEEN VAN BOVENSTAANDE*	e.
5.	**STABILITEIT VAN DE GEZOND-HEIDS-PROBLEMEN**	Door problemen/ziekten zijn de cognitie-, ADL-, stemmings- of gedrags-functies onstabiel—(wisselvallig, precair, verergerend)			a.
		Patiënt maakt een acute episode of opleving mee van een terugkerend of chronisch gezondheidsprobleem			b.
		Eindstadiumziekte, 6 maanden of korter te leven			c.
		GEEN VAN BOVENSTAANDE			d.

SECTIE K. VOEDINGSTOESTAND

1.	**MOND-PROBLEMEN**	Kauwprobleem			a.
		Slikprobleem			b.
		Mondpijn			c.
		GEEN VAN BOVENSTAANDE			d.
2.	**LENGTE EN GEWICHT**	*Noteer **(a.) lengte in cm's** en **(b.) gewicht in kg's**. Baseer het gewicht op de meest recente meting in de **laatste 30 dagen**; meet het gewicht op de standaardwijze—bv., in de ochtend, na de toiletgang, vóór het ontbijt, met schoenen uit, in nachtkledij* **a.** LEN (cm.) ___ ___ ___ **b.** GEW (kg.) ___ ___ ___			
3.	**VERANDE-RING IN GEWICHT**	**a. Gewichtsverlies**—5 % or meer in de **laatste 30 dagen**; of 10 % of meer in de **laatste 180 dagen** 0. Nee 1. Ja			
		b. Gewichtstoename—5 % or meer in de **laatste 30 dagen**; of 10 % of meer in de **laatste 180 dagen** 0. Nee 1. Ja			
4.	**EET-PROBLEMEN**	Klaagt over de smaak van veel van het voedsel	a.	Laat bij de meeste maaltijden 25% of meer van eten staan	c.
		Regelmatig of herhaaldelijk klagen over honger	b.	*GEEN VAN BOVENSTAANDE*	d.
5.	**VOEDINGS-AANPAK**	(***Kruis aan wat in de laatste 7 dagen van toepassing is***)			
		Parenterale-/IV-voeding	a.	Voedingssupplement tussen maaltijden	f.
		Voedingssonde	b.		
		Mechanisch bewerkt dieet	c.	Vastgezet bord, aangepast bestek, enz.	g.
		Voeding met spuit (oraal)	d.		
		Therapeutisch dieet	e.	Neemt deel aan gewichts-veranderingskuur	h.
				GEEN VAN BOVENSTAANDE	i.
6.	**PARENTE-RALE OF ENTERALE VOEDSEL-OPNAME**	(***Ga naar Sectie L als 5a of 5b beide niet zijn aangekruist***) **a.** Codeer het aandeel in **calorieën** dat de patiënt door parenterale- of sondevoedingen in de **laatste 7 dagen** ontving 0. Geen 1. 1 - 25% 2. 26 - 50% 3. 51 - 75% 4. 76 - 100% **b.** Codeer de gem. IV- of sonde-**vochtopname** in de **laatste 7 dagen** 0. Geen 1. 1 - 500 cc/dag 2. 501 - 1000 cc/dag 3. 1001 - 1500 cc/dag 4. 1501 - 2000 cc/dag 5. 2001 en meer cc/dag			

SECTIE L. TOESTAND VAN DE MOND/GEBIT

1.	**TOESTAND EN ZIEKTE-PREVENTIE VAN DE MOND**	Brokstukjes (zacht, gemakkelijk te verwijderen) aanwezig in de mond voor het naar bed gaan 's avonds	a.
		Heeft een kunstgebit en/of uitneembare brug	b.
		Enige/alle eigen tanden kwijt—heeft geen of gebruikt geen kunstgebit (of gedeeltelijke gebitsplaten)	c.
		Afgebroken, losse of rotte tanden	d.
		Ontstoken tandvlees; opgezwollen of bloedend tandvlees; abcessen in de mond; zweren of uitslag	e.
		Dagelijks schoonmaken van tanden/kunstgebit—door de patiënt zelf of door zorgverleners	f.
		GEEN VAN BOVENSTAANDE	g.

SECTIE M. CONDITIE VAN DE HUID

1.	**ZWEREN** **(Waardoor dan ook)**	*(Noteer het aantal zweren op elk stadium—ongeacht de oorzaak. Als er geen zweer is, codeer dan "0" (nul). Codeer al wat in de **laatste 7 dagen** van toepassing is. Code 9 = 9 of meer.)* ***[Een volledig lichamelijk onderzoek is noodzakelijk.]***		**Aantal op stadium**
		a. Stadium 1. Een blijvend stuk rode huid (zonder dat de huid kapot is) dat niet verdwijnt wanneer de druk erop is opgeheven.		
		b. Stadium 2. Een gedeeltelijk dikteverlies van de huid dat zich klinisch als een ontvelling, blaar of ondiep gat voordoet		
		c. Stadium 3. De volledige huiddikte is verloren gegaan. De onderhuidse weefsels liggen bloot. Dit doet zich voor als een diep gat met of zonder ondermijning van naastgelegen weefsel		
		d. Stadium 4. De volledige huiddikte en het onderhuids weefsel is verloren gegaan. Spieren en/of bot liggen bloot.		
2.	**SOORT ZWEER**	(*Voor elke zweer, **codeer het hoogste stadium in de laatste 7 dagen**. Gebruik de schaal van M1—d.w.z., stadia 0 - 4*)		
		a. Decubitus ulcus—wond veroorzaakt door druk resulterend in schade van het onderliggende weefsel		
		b. Ulcus van de venen—open wond die veroorzaakt wordt door een slechte bloedcirculatie met name in de onderbenen		
3.	**ZWEREN DIE ZIJN GENEZEN**	Patiënt had een zweer die **in de LAATSTE 90 DAGEN** is verdwenen/genezen 0. Nee 1. Ja		
4.	**ANDERE HUID-PROBLEMEN OF KAPOTTE HUID**	(***Kruis alle problemen van de laatste 7 dagen aan***)		
		Schrammen, builen		a.
		Brandwonden (tweede- of derdegraads)		b.
		Open wonden, geen zweren, uitslag, snijwonden (bv., kankerwonden)		c.
		Huiduitslag --intertrigo, eczeem, medicijn-, hitte-uitslag, herpes zoster		d.
		Huid ongevoelig voor pijn of druk		e.
		Huidsneetjes (anders dan door operaties)		f.
		Operatiewonden		g.
		GEEN VAN BOVENSTAANDE		h.
5.	**HUID-BEHANDE-LINGEN**	(***Kruis alle behandelingen van de laatste 7 dagen aan)***		
		Drukontlastingsmiddel(en) voor in de stoel		a.
		Drukontlastingsmiddel(en) voor in bed		b.
		Wisselliggingsprogramma		c.
		Voedings- of vochttoedieningsinterventie voor huidproblemen		d.
		Ulcusverzorging		e.
		Operatiewondverzorging		f.
		Verband (met of zonder plaatselijk toegepaste medicijnen), niet voor de voeten		g.
		Zalf/medicijnen (niet voor de voeten)		h.
		Andere preventieve/beschermende huidzorg (niet voor de voeten)		i.
		GEEN VAN BOVENSTAANDE		j.
6.	**VOET-PROBLEMEN EN VOET-VERZOR-GING**	(***Kruis aan wat van toepassing is in de laatste 7 dagen***)		
		Patiënt heeft één of meer voetproblemen—bv., likdoorns, eelt, knobbels, hamertenen, overlapping, pijn, slechte structuur		a.
		Voetinfectie—bv., voetschimmel, etteruitscheiding		b.
		Open wonden aan de voet		c.
		Nagels/eelt gedurende de **laatste 90 dagen** bijgeknipt		d.
		Kreeg preventieve of beschermende voetzorg (bv., gebruikte speciale schoenen, inleggers, kussentjes, teenscheiders, steunkousen)		e.
		Verband (met of zonder plaatselijk toegepaste medicijnen)		f.
		GEEN VAN BOVENSTAANDE		g.

SECTIE N. ACTIVITEITEN VERRICHTINGENPATROON

1.	**TIJD DAT DE PATIENT WAKKER IS**	(***Kruis de betreffende tijdsperioden over de laatste 7 dagen aan***) Patiënt is bijna altijd wakker (d.w.z. slaapt niet langer dan een uur per dagdeel) in de:			
		Ochtend	a.	Avond	c.
		Namiddag	b.	*GEEN VAN BOVENSTAANDE*	d.
(Als de patiënt comateus is, ga dan naar Sectie O)					
2.	**TIJD GEMID. BETROKKEN BIJ ACTIVI-TEITEN**	(**Wakker, terwijl men niet wordt behandeld of ADL-zorg ontvangt**) 0. Meestentijds—2/3 of meer 1. Enige tijd—1/3 - 2/3 2. Weing tijd—minder dan 1/3 3. Geen tijd			
3.	**VOORKEUR-SETTINGS VOOR ACTIVI-TEITEN**	(***Kuis alle voorkeursettings** voor activiteiten aan*)			
		Eigen kamer	a.	Buiten de instelling	d.
		Dag-/activiteitenkamer	b.		
		In vph/weg van afdeling	c.	*GEEN VAN BOVENSTAANDE*	e.
4.	**ALGEMENE VOORKEUR VOOR ACTIVI-TEITEN (afgestemd op de huidige mogelijkheden van de patiënt)**	(***Kruis alle voorkeuren aan,** ook als de activiteit op dit moment niet voor de patiënt beschikbaar is*)			
		Kaarten/spelletjes	a.	Uitstapjes/winkelen	g.
		Handwerk/kunst	b.	Wandelen/in rolstoel naar buiten	h.
		Oefeningen/sport	c.	TV-kijken	i.
		Muziek	d.	Tuinieren of verzorgen van planten	j.
		Lezen/schrijven	e.	(Gezellig) praten	k.
		Geestelijke/godsdienstige activiteiten	f.	Helpen van anderen	l.
				GEEN VAN BOVENSTAANDE	m.

Patiënt _____ Identificatienummer _____

5.	**WIL GRAAG VERANDERING IN DAGELIJKSE ROUTINE**	*Codeer wat de patiënt ten aanzien van de dagelijkse routines graag wil* 0. Geen verandering 1. Geringe verandering 2. Belangrijke verandering **a.** Soort van activiteiten waar de patiënt momenteel aan meedoet **b.** Mate waarin de patiënt bij de activiteiten is betrokken

SECTIE O. MEDICIJNGEBRUIK

1.	**AANTAL MEDICIJNEN**	(***Noteer het aantal verschillende*** *medicijnen dat in de* ***laatste 7 dagen*** *is gebruikt; noteer "0" als geen enkele is gebruikt*)
2.	**NIEUWE MEDICIJNEN**	*Patiënt gebruikt op dit moment medicijnen waarmee in de* ***laatste 90 dagen*** *is begonnen* 0. Nee 1. Ja
3.	**INJECTIES**	(***Noteer het aantal DAGEN*** *waarop de patiënt gedurende de* ***laatste 7 dagen*** *injecties ontving; noteer "0" bij geen enkele*)
4.	**DAGEN WAAROP DE VOLGENDE MEDICIJNEN ZIJN ONTVANGEN**	(***Noteer het aantal DAGEN*** *in de* ***laatste 7 dagen****; vul "0" in bij geen. Voor medicijnen die langer werkzaam zijn dan een week: tel als "1"*) **a.** Antipsychotica **b.** Anxiolytica **c.** Antidepressiva **d.** Hypnotica **e.** Diuretica

SECTIE P. SPECIALE BEHANDELINGEN EN PROCEDURES

1. SPECIALE BEHANDELINGEN, PROCEDURES EN PROGRAMMA'S

a. SPECIALE ZORG—*Kruis* *ontvangen behandelingen en programma's aan van de* ***laatste 14 dagen*** **[Let op—tel alleen behandelingen van na de opname]**

BEHANDELINGEN

- Chemotherapie — a.
- Dialyse — b.
- IV-medicijnen — c.
- Intake/output-meting — d.
- Monitoring van acuut medisch probleem — e.
- Stomazorg — f.
- Zuurstoftherapie — g.
- Bestraling — h.
- Uitzuigen — i.
- Tracheostomazorg — j.
- Transfusies — k.
- Ventilator of beademapparaat — l.

PROGRAMMA'S

- Alcohol & drugs-behandelprogramma — m.
- Verblijf op psychogeriatrische afdeling — n.
- Hospice-zorg — o.
- Verblijf op pediatrie afdeling — p.
- Vakantie-opname — q.
- Training van vaardigheden nodig voor terugkeer naar huis (bv., medicijnen innemen, huishouden, boodschappen doen, vervoer, ADL's) — r.
- *GEEN VAN BOVENSTAANDE* — s.

b. THERAPIEËN - *Leg het aantal dagen en min. vast dat op de* ***laatste 7 kalenderdagen*** *elk van de volgende therapieën meer dan 15 min./dag is gegeven. (Vul "0" in indien niet of bij minder dan 15 min./dag)* **[Let op—tel alleen therapieën van na de opname]**

(A) = # dagen gegeven van **15 minuten of langer**
(B) = totaal # minuten gegeven in de **laatste 7 dagen**

	DAGEN (A)	MINUTEN (B)
a. Logopedie en audiologie		
b. Ergotherapie		
c. Fysiotherapie		
d. Ademhalingstherapie		
e. Psychotherapie (door bevoegd therapeut)		

2. INTERVENTIE-PROGRAMMA'S VOOR STEMMING, GEDRAG, COGNITIEVERLIES

(**Kruis alle interventies of strategieën aan**, ongeacht waar, die in de **laatste 7 dagen** zijn ontvangen)

- Speciaal programma voor de evaluatie van gedragssymptomen — a.
- Evaluatie in de **laatste 90 dagen** door een bevoegd psychotherapeut — b.
- Groepstherapie — c.
- Patiëntgerichte weloverwogen veranderingen in de omgeving om stemming/gedrag te veranderen—bv., kast geven om in te rommelen — d.
- Heroriëntatie-therapie—bv., bewegwijzeren — e.
- *GEEN VAN BOVENSTAANDE* — f.

3. VERPLEEGKUNDIGE REVALIDATIE/ REACTIVERING

Leg het AANTAL DAGEN vast dat op de ***laatste 7 dagen*** *elk van de volgende verpleegkundige revalidatie- of reactiveringstechnieken* ***15 min./dag of meer*** *is gegeven. (Vul "0" in indien niet of bij minder dan 15 min./dag)*

- **a.** Bewegingsuitslag (passief)
- **b.** Bewegingsuitslag (actief)
- **c.** Hulp bij spalk of tuigje
- **TRAINING EN VAARDIGHEIDSPRAKTIJK IN:**
- **d.** Bedbeweeglijkheid
- **e.** Transfer
- **f.** Lopen
- **g.** Kleden/zich wassen
- **h.** Eten of slikken
- **i.** Stomp-/prothesezorg
- **j.** Communicatie
- **k.** Andere

4.	**MIDDELEN EN MAATREGELEN VOOR LICHAAMSFIXATIE**	(*Gebruik de volgende codes voor wat betreft de* ***laatste 7 dagen***:) 0. Niet gebruikt 1. Minder vaak dan dagelijks gebruikt 2. Dagelijks gebruikt Bedhekken **a.** — Volledige hekken aan alle open kanten van het bed **b.** — Andere soorten bedhekken (bv., half-hek, aan één kant) **c.** Bovenlichaamfixatie **d.** Ledemaatfixatie **e.** Stoel waaruit de patiënt niet kan opstaan
5.	**VERBLIJF IN ZIEKENHUIS**	Leg het aantal keren vast dat de patiënt **in de laatste 90 dagen** (of sinds de laatste beoordeling daarna) tenminste 1 nacht in een ziekenhuis heeft doorgebracht. (*Vul "0 " in bij geen opnames*)
6.	**BEZOEK AAN EHBO-KLINIEK**	Leg het aantal keren vast dat de patiënt **in de laatste 90 dagen** (of sinds de laatste beoordeling daarna) zonder overnachting de EHBO-kliniek heeft bezocht. (*Vul "0 " in bij geen bezoeken*)
7.	**ARTS-VISITES**	Op hoeveel dagen in de **LAATSTE 14 DAGEN** (of sinds de opname als dit kortergeleden is) heeft een arts (of bevoegd assistent) de patiënt onderzocht? (*Vul "0" in bij geen*)
8.	**DOKTERS-VOORSCHRIFTEN**	Op hoeveel dagen in de **LAATSTE 14 DAGEN** (of sinds de opname als dit kortergeleden is) heeft een arts (of bevoegd assistent) de doktersvoorschriften voor de patiënt veranderd? *Tel verlengingen van bestaande recepten niet mee.* (*Vul "0" in bij geen*)
9.	**AFWIJKENDE LABORATORIUM-WAARDEN**	Heeft de patiënt gedurende de **laatste 90 dagen** (of sinds de opname) een uitslag van afwijkende laboratoriumwaarden gehad? 0. Nee 1. Ja

SECTIE Q. ONTSLAGMOGELIJKHEID EN ALGEHELE TOESTAND

1.	**ONTSLAG-MOGELIJKHEID**	**a.** Uit/geeft de patiënt de wens aan voor terugkeer naar huis? 0. Nee 1. Ja **b.** Heeft de patiënt de steun van iemand die positief staat tegenover ontslag? 0. Nee 1. Ja **c.** Prognose van kort-verblijf— ontslag **binnen 90 dagen** gepland (omvat niet het sterven voor die datum) 0. Nee 2. Binnen 31 - 90 dagen 1. Binnen 30 dagen 3. Onslag-status onzeker
2.	**ALGEHELE VERANDERING IN ZORGBEHOEFTEN**	De algehele zelfredzaamheid van de patiënt is ten opzichte van de toestand van **90 dagen geleden** (of sinds de beoordeling daarna) wezenlijk veranderd 0. Geen verandering 1. Verbeterd—minder ondersteuning, minder hoog zorgniveau nodig 2. Verslechterd—ontvangt meer ondersteuning